

NANCE-FLOYD, BETTY, Ph.D. A Qualitative Study to Understand the Perception of Illness and the Decision Making Process for Accessing and Utilizing Health Care for American Indians in Southeastern, NC. (2016)
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The purpose of this study was to understand the perceptions and experiences of illness among American Indians (AI) in southeastern NC and to describe their decision making processes when accessing and using health care services. Most AIs in North Carolina live in rural areas, where chronic illnesses are a growing concern. Illnesses such as cardiovascular diseases and diabetes have crippled this population physically and emotionally and have resulted in undue financial hardship for AIs.

Focused ethnography methodology was used to guide the study and the Social-Ecological Model (SEM) aided in the analysis of the data. AI gatekeepers recruited eighteen participants from rural areas to participate in one of four focus groups or one of three semi-structured interviews. After data analysis, confirmation of findings was received from the participants.

These participants describe illness as having a medical diagnosis and the experience of being ill as having signs and symptoms, for example, breathing difficulty, pain, bleeding, inability to attend social functions, and the inability to be active. Many of these participants reported seeking care for primary, secondary and tertiary prevention. Factors that influenced their decision making involved all of the SEM levels. The two most significant factors that influenced their decision making to seek health care were adequate insurance and a relationship with the provider. With the exception of an emergency, without these two factors, there was a delay in seeking health care.

A QUALITATIVE STUDY TO UNDERSTAND THE PERCEPTION OF ILLNESS
AND THE DECISION MAKING PROCESS FOR ACCESSING AND
UTILIZING HEALTH CARE FOR AMERICAN INDIANS
IN SOUTHEASTERN, NC

by

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Approved by

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I dedicate this work to my husband, Jim, whose daily encouragement and unwavering support assisted me to complete this journey.

APPROVAL PAGE

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CHAPTER I

INTRODUCTION

There are 6.2 million American Indians (AI) living in the United States (US) who reside on reservations (22 %), in metropolitan areas (60%) or on rural non-federally trusted land (US Federal Government, Indian Health Services, 2015). Through the Constitution of the United States (US), treaties, court decisions and federal statutes, the US has a unique government-to-government relationship with the federally recognized tribes. It is important to understand that this relationship is with federally recognized tribes only. North Carolina (NC) has the largest American Indian population east of the Mississippi River and the seventh largest American Indian population in the nation according to 2010 U.S. Census Bureau (NC Commission of Indian Affairs, 2015). North Carolina has eight AI tribes. The Eastern Band of Cherokee is the only NC tribe that is fully federally recognized (NC Commission of Indian Affairs, 2015). The remaining seven, Coharie, Haliwa-Saponi, Lumbee, Meherrin Indian, Occaneechi Band of Saponi Nation, Sappony, and the Waccamaw Siouan tribes are state recognized (NC Commission of Indian Affairs, 2015). After the Lumbee Act of 1956, the Lumbee Tribe received partial federal recognition (UNC American Indian Center, 2016; NC Commission of Indian Affairs, 2015). This act states that the Lumbee are not eligible for any Indian services from the United States because of their status as Indians (Indian

Affairs: Laws and Treaties, 2016). Thus, the Lumbee Indians do not receive federal benefits.

The leading causes of mortality for AIs in the United States are heart disease, cancer, unintentional injury, and diabetes (US Department of Health and Human Services, Office of Minority Health, 2015). The majority of AIs in NC live in Robeson County and surrounding counties. Other southeastern tribes are the Coharie Tribe whose members mostly live in Sampson and Harnett Counties (NC Commission of Indian Affairs, 2015). The Waccamaw-Siouan Tribal members live in Bladen and Columbus Counties (NC Commission of Indian Affairs, 2015). The State of the County Health (SOTCH) reports for 2014 and 2015 (2014/2015) rankings for health outcomes for the following counties were: Bladen, 91/88; Columbus, 100/100; Cumberland, 73/73; Harnett, 50/44; Robeson, 97/95; Sampson, 81/70; and Scotland, 98/98 (100 counties in NC; score of 1 is best and 100 is worst) (County Health Rankings & Roadmaps, 2015).

In Nance-Floyd's (Manuscript in preparation, 2015) work titled *Focused ethnography study to examine current health status of Native Americans in Eastern North Carolina*, unexpected findings regarding what illness meant to this group emerged. For those participants, illness was considered a part of how physically functional a person was at a particular time. For example, if a person was able to function in his/her normal life, include rising from bed or going to work and social events, he would consider himself well (healthy) and not in need of health care. If a person was unable to get out of bed or complete his/her normal daily routine, he/she *may* consider himself to be sick. These findings will be discussed in more detail in chapter 2. It was this data that

informed the need to study the meaning of illness and the decision making processes used by this group regarding access and utilization of health care. It is generally accepted that receiving primary health care is one of the best ways to promote health and wellness among persons. In addition, when illnesses do occur, it is important that these be identified early so that effective treatments can be initiated in order to prevent negative outcomes. If American Indians are not seeking well care to maintain their wellness and not having illnesses identified early in the illness trajectory in order to receive treatment, these behaviors could be a major contributor to health disparities they face.

Purpose of Study

The purpose of this study was to understand the perceptions and experiences of illness among American Indians in southeastern NC and to describe their decision making processes when accessing and using health care services. It was important to understand how illness was described by persons in this population, and further, to identify their decision making motivators and barriers for seeking health care. By understanding these aspects of health care seeking by American Indians, interventions can be designed and tested that could help to improve health outcomes for this group. Without this understanding, poor health outcomes for this group could continue.

Although AIs share many common health disparities, it is important to understand the history and resources that differ between the federally recognized and the state recognized tribes as this could affect access and utilization of health care for these different groups in different ways. State recognized tribes remain without designated Indian land that was identified when federal treaties were signed (NC Commission of

Indian Affairs, 2015) during the treaty era from 1778 and 1871 (Bureau of Indian Affairs, 2015). The state tribes do not live on reservations and are members of their communities at large as they pay city, county, state, and federal property and income taxes, attend state public schools, are leaders and members of social and community organizations, and rely on non-Indian health services for health care (Oakley, 2005).

State tribes do not have access to the estimated federally allocated 4.4 billion dollars to the Indian Health Services (IHS). These funds provide practical access to clinics for mental health, dental, eye care, rehabilitation, health education, social services, pharmacy services, and home health care (US Federal Government, Indian Health Services, 2015). With some guidance from the US Bureau of Indian Affairs, federal tribes govern their US federally allocated money, as they see fit, allowing more culturally sensitive allocation of funds. Because federal tribe residents are entitled to these Indian Health Services and have an organized health care system, these residents have the potential to interact with more health care facilities and receive better health care as compared to their non-federally recognized counterparts (US Federal Government, Indian Health Services, 2015).

Unfortunately, because the state recognized tribes were not included in any of the federal treaties, they do not have access to the IHS and therefore must take their own initiative to purchase and access health care. Both federal and state recognized AI individuals, if they meet eligibility criteria, may access education, health, welfare, and other social services programs that are available to all US citizens (Bureau of Indian Affairs, 2015). In addition to following the local, state and federal policies and political

influences of health care, there is a Tribal Council for each federal and state tribe. AI communities organize a Tribal Council to address their own disparities and interests.

Nonetheless, federal and state AI tribes suffer from health disparities deeply embedded in the AI culture and lifestyle. Most American Indians in North Carolina live in rural areas, and as with most rural areas in NC, have limited access to primary health care and suffer from socioeconomic demise. Hence, focusing on North Carolina state recognized tribes is relevant to those American Indian citizens and to the state.

According to the 2010 census, there were 122,110 AI (184,082 who classified themselves as AI alone and/or in combination with another ethnic group) North Carolinians (NC Commission of Indian Affairs, 2015). This number represents more than one percent of the total population of the state (NC Commission of Indian Affairs, 2015). The 2014 NC socioeconomic data reveals that 81.9% percent of AIs earned a high school education compared to 82.0% for African Americans (AAs) and 88.0% for whites; the unemployment rate for AIs was 5.3 percent, compared to 8.5 percent for AAs and 4.0 percent for whites; the mean household income was \$33,094 for AIs compared to \$33,022 for AAs and \$51,707 for whites; medically uninsured rates for AIs was 17.8% compared to 14.3% for AAs and 11.5% for whites; and the poverty rate was 27.9% for AIs compared to 26.5% for AAs and 13.3% for whites (North Carolina State Center for Health Statistics, 2015). The percentage of AI families in NC living below the federal poverty level in 2008 was 21.2 % and has risen to 27.9% in the 2014 report (North Carolina State Center for Health Statistics, 2015). These statistics highlight this forgotten

population and reflect issues related to the alarming health disparities that they are suffering.

In general, many of the southeastern counties in NC where AIs live are considered poor and rural counties. For example, the percentage of AIs among the total county population for the rural southeastern NC counties in 2014 were Bladen County 2.9 %, Columbus County 3.5 %, Robeson County 39.7%, Scotland County 11.4%, and Sampson County 3.1% (US Census Bureau, Quick Facts, 2016). According to the US Census Bureau Quick Facts (2016) the percentage of people living in poverty in these selected counties are: Bladen County 25.6%, Columbus County 24.3%, Robeson County 33.1%, Scotland County 28.9%, and Sampson County 20.0%. The number of people in these counties under the age of 65 who are without insurance are Bladen County 20.3%, Columbus County 20.5%, Robeson County 24.7%, Scotland 18.3%, and Sampson County 24.0% (US Census Bureau, Quick Facts, 2016).

Robeson County is home to forty-five percent of the 122,110 AIs living in NC (NC Commission of Indian Affairs, 2015). The mean household income in Robeson County was \$29,965 in 2014 (County Health Rankings & Roadmaps, 2015). The Robeson County Health Department's (2013) latest published SOTCH report acknowledged the lack of providers (1594 people per primary care physician compared to 1158 in NC and 926 people per nurse practitioner compared to 714 in NC) and the lack of buses and public transportation for accessing health care in rural areas. The trends in low wages, non-professional jobs, lack of health insurance, and poverty continue to be barriers to access, cost, and use of health care. The North Carolina Medical Journal

reports that non-white people living in poor rural settings in eastern NC have a higher risk of chronic illnesses than their white counterparts (Bertoni, Ensley, & Goff, 2012; O'Connell & Vetter, 2012). Clearly, AIs are at high risk for chronic illnesses.

The Problem: Background and Significance

The leading causes of mortality for AIs in the United States include heart disease, cancer, unintentional injury, and diabetes (Bertoni, Ensley, & Goff, 2012; Jaremo & Aman, 2011; US Department of Health and Human Services, Office of Minority Health, 2015; Robeson County Health Department, 2013). In the Center for Disease Control and Prevention's (CDC) *Health Disparities & Inequalities Report 2013* (CHDIR), important health disparities were noted for the combined population of American Indians and Alaskan Natives. Below is a summary.

- In 2006, AIs had a 48.4% greater infant death rate than whites which represents the second highest (African American was first) infant death rate compared with other mothers.
- In 2007, American Indians and Alaskan Natives had disproportionately high death rates from unintentional injuries and suicide to include motor vehicle-related deaths and injury or death due to illicit, prescription, and over-the-counter medications and drugs compared with other racial/ethnic populations in the US.
- In 2008, the birth rate among females 10-19 years of age was the third highest in the nation; the percentage of adults' aged 50 years and older who received colorectal screening was 9% less than the percentage of white adults screened.

- In 2009, adults from these groups were among those with the highest frequency of binge drinking to include one of the highest number of binge drinking episodes per individual, and the highest number of drinks consumed during binge drinking; those in these groups ages 12-18 years and older had the highest occurrence of smoking compared with other racial/ethnic populations; the incidence among American Indian and Alaskan Native adults who did not complete high school was 127.3% higher than the incidence among white adults; and similar to African Americans and Hispanics, twelve percent (12%) more of these adults lived below the federal poverty level, as compared with white adults.
- In 2010, the tuberculosis rate for adults in these groups was 5.8 compared to 2.0 for whites.
- In, 2010, 41 % of NAs had private health insurance coverage, 36.7 % relied on Medicaid, and 29.2 % had no health insurance coverage (CDC, CHDIR, 2015).

North Carolina's 2015 health ranking is 31 out of the 50 states (1 is the best; 50 is the worst) (American's Health Rankings, 2016). The Centers for Disease Control and Prevention, National Center for Health Statistics (2015) acknowledged cardiovascular disease (CVD) as the most concerning chronic illness because it exacerbates many secondary illnesses while leading to high mortality and morbidity. MAP-IT (Mobilized, Assess, Plan, Implement, Track) for community based interventions statistical data indicated that NC has a 32% higher prevalence of chronic illnesses to include heart

disease, strokes, and diabetes as compared to other states (US Department of Health and Human Services, 2015). Strokes are closely related to and many times secondary to CVD and coronary heart disease (CHD) (Bertoni, Ensley, & Goff, 2012). In 2011, cardiovascular disease alone cost NC Medicaid approximately \$621 million (O'Connell & Vetter, 2012).

The NC Office of Minority Health and Health Disparities and the State Center for Health Statistics (2015) latest data from 2010-2014 revealed that heart disease was the leading cause of death for American Indians in NC followed by cancer. At the time of this writing, the 2014 Robeson County SOTCH report had not been published. However, the county Health Rankings and Roadmaps produced in collaboration between the Robert Wood Johnson Foundation and the University of Wisconsin Population Health Institute from which the rankings and data for the SOTCH report are taken indicated that Robeson County's Health Outcomes ranking was 97 and its Health Factor ranking was 100 (County Health Rankings & Roadmaps, 2015). On a scale of 1 to 100, it is important to remember that 1 is best and 100 reflects the worst state ranking in a given area. Health Rankings and Roadmaps ranked Robeson County number 98 for length of life, 87 for quality of life, 99 for health behaviors, 99 for clinical care, 99 for social and economic factors, and 36 for physical environment (County Health Rankings & Roadmaps, 2015). Clearly, those living in this geographic area are facing many health inequities. Since 39% of the people living in Robeson County are AI, it is clear that these persons are facing barriers to good health and positive health outcomes.

Issues Related to Access and Utilization of Health Care

The lack of health care access and utilization contributes to the lack of quality care which has led to chronic illnesses and higher mortality and morbidity rates for these AIs. The cost of chronic illness is not only emotionally challenging and financially crippling to patients and their caregivers, the costs place excessive burden on limited health care resources in the state. The National Healthcare Expenditure Projections for 2010-2020 indicate that the US has the most costly health care system in the world with health care costs accounting for nearly 17% of the gross domestic product (The Commonwealth Foundation, 2014). These data also ranked the US behind most countries in health outcomes, quality and efficiency of health care (The Commonwealth Foundation, 2014). More specifically, in 2013 when the US was compared to ten other industrialized countries (Austria, Canada, France, Germany, Netherlands, New Zealand, Norway, Sweden, Switzerland, and United Kingdom), in terms of quality of care, access to care, efficiency, equity, and healthy lives, the United States' overall rank was eleven out of eleven or last place (The Washington Post, 2014). Ironically, health expenditures for the US were the highest of any comparable country (The Washington Post, 2014). According to these data, the US is weak on providing access to health care for its citizens, leaving much room for improvement. One of the best ways to make significant changes in the US health care system is to start with those that are most desperate or in need, with the poorest outcomes. Clearly, efforts are needed to promote the most effective and efficient way to provide care to all Americans. However, since AIs in NC are facing enormous health inequities, far beyond those faced by the majority of Americans,

studying this group was of critical importance. Unfortunately, access to health care had not been studied for AIs in general.

Historically, AIs have been community-centered with particularly great allegiance to their tribe (Smyer & Clark, 2011). American Indians mistrust non-American Indian leaders and health care professionals, and, in general, believe in natural healing (Cavanaugh, Taylor, Keim, Clutter, & Geraghty, 2008; Daher, 2012; Smyer & Clark, 2011). Both of these facts are assumed to contribute to issues and trends related to AIs not seeking traditional health care. Other issues related to access to health care for AIs include social and cultural norms, lack of money, insurance, transportation, health care providers, and funding for clinics (US Department of Health And Human Services, Office of Minority Health, 2015). Some studies identified AI's perception to time orientation that was focused on past history versus future needs as providing rationale for why they have little concern with future events such as being on time for doctor appointments (Munoz & Luckmann, 2005) or seeking health care or preventive measures (Dochterman & Grace, 2001). Certainly, cultural norms have played a key role in the health care of AIs. Yet, cultural values alone are not the major contributor to the poor health of AIs.

Without access to health care, health promotion and prevention of illness options cannot be delivered to those in need. Additionally, if available services are not utilized, simple illnesses may become chronic problems which often lead to poor quality of life and financial hardship. With the growing incidence of chronic illnesses such as stroke, cardiovascular disease, and diabetes and the enormous strain the cost of these diseases

places on the health care system in rural communities, studies are needed to better understand AI's current access and utilization of health care services before specific interventions to promote improvements can be designed.

National Initiatives for Access and Utilization

The state recognized AI tribes and communities in NC are populations struggling from health disparities and inequalities. They are considered high-risk, high-cost populations and qualify under the law to receive all initiatives for healthier populations. The Patient Protection and Affordable Care Act (ACA) addressed access to health care in multiple strategies, including but not limited to, restructuring the Medicare payment regulations, increasing payment for health care in underserved populations, increasing educational grants for primary care practitioners, financing quality improvement efforts, increasing insurance availability for the uninsured and low income, and increasing workplace insurance (Estes, Chapman, Dodd, Hollister, & Harrington, 2013; National Partnership for Women & Families, 2011). These goals have allowed communities to reach local objectives through federal grant funding. Estes and colleagues (2013) explained how the ACA has helped to improve delivery of health care through 11 billion dollars in federal grants for community-based collaborative care programs, new trauma centers, school-based health centers (North, McElligot, Douglas, & Martin, 2012) and nurse-managed clinics, and 1.5 billion dollars in National Health services. Under the ACA, some citizens, who previously did not, now qualify for Medicaid. Unfortunately, for the uninsured in NC, the ACA Medicaid extension option is currently not available.

In addition to access to health care, the ACA specifically addressed population health in four areas:

1. Expansion of insurance coverage, for example, through individual mandate, Medicaid expansions and state insurance exchanges with an aim to improve health by improving access to care.
2. Improving the quality of care with National Strategy for Quality Improvement, Center for Medicare and Medicaid Innovation, and efforts from the Patient-Centered Outcomes Research Institute (PCORI).
3. Enhance prevention and health promotion actions within the health care system. One element is the implementation of new health care models (Accountable Care Organizations [ACO] and Patient Centered Medical Homes [PCMH]) requiring providers to take responsibility for population health outcomes.
4. Promote community and population based activities through already established and new inspirations from organizations such as the National Prevention, Health Promotion and Public Health Council and incentives for workplace wellness programs (Stoto, 2013).

The Institute for Healthcare Improvement (IHI)'s framework to improve population health is called the Triple Aim; it includes a) improving the patient experience of care, b) improving the health of the population (health and functional status, risk status, disease burden, mortality rates, and remaining years of life in good health), and c) reducing per capita cost of care (IHI, 2015). The IHI's Triple Aim for Populations

(2015) proposed new models of population health management. The focus was on high-risk, high-cost populations (IHI, Triple Aim for Populations, 2015). They have campaigned with specific focus to reduce disparities or inequities, assist in building skills to improve population health, and provide assessment, design, and capability for strategic planning (IHI, Triple Aim for Populations, 2015). The AI community is a high-risk, high-cost population who has suffered decades of discrimination and disparity and now suffers chronic illnesses and high mortality rates. The Centers for Medicare and Medicaid Services (CMS) (2015) offered several health care models to improve care including - the ACO and PCMH. Both models focus on population health management by creating *partnerships* between the patient and the practice through better coordination of care (Centers for Medicare & Medicaid Services, 2015).

Beginning in 2015, because of initiatives in the ACA, a phase-in reimbursement process for providers will be financially compensated through value-based payments and population health management (CMS, 2015). In the past, providers had been paid through a fee-for-service billing and payment model. Provider reimbursement will be directly linked to patient outcomes, not volume of services. The final phase-in for the new reimbursement process will be completed in 2017. If providers do not meet calendar year quality indicators, they are subject to a reimbursement penalty (CMS, 2015).

This new reimbursement incentive opens conversational opportunities regarding the health of the broader population, the American Indian population, and health outcomes. Now that providers will be reimbursed based on the health of the population they serve while trimming costs, prevention of diseases and health promotion

interventions will be imperative. Particularly since there is a lack of primary care providers (PCP) in rural southeastern NC, health partnerships between PCPs and AIs will be vital. New studies that focus on understanding health and illness from the AI perspective are necessary to build partnerships and ultimately successful interventions for the AI community; otherwise, the American Indians will continue to be a population of despair with poor health outcomes.

Local Access and Utilization

Robeson County's health services division provides care to the largest population of AIs in NC. The Robeson County SOTCH report acknowledges the lack of health providers as well as limited public transportation in this rural area (Robeson County Health Department, 2013). There is one hospital that serves the county. Southeastern Health is a non-profit organization that offers Magnet hospital status and services (quality patient care, nursing excellence and innovations in professional nursing practices) in Lumberton located in Robeson County, NC. The hospital is licensed for acute, intensive care and psychiatric services using 452 total beds for more than 16,000 inpatients and 76,000 emergency department patients annually (Southeastern Health, 2014). In terms of outpatient medicine, Southeastern Health offers primary care from medical doctors (MD), doctors of osteopathic medicine (DO), nurse practitioners (NP), and physician assistants (PA) via 14 primary care clinics throughout the county (Southeastern Health, 2014).

Although heart disease is the number one cause of death for AIs (CDC, Nation Center for Health Statistics, 2015; Robeson County Health Department, 2013; US Department Of Health and Human Services Office of Minority Health, 2014), the

numbers have decreased (2002-2006 cardiac related deaths rate of 297.9; compared to 2007-2011 rate of 226.7) in Robeson County (Robeson County Health Department, 2013). The SOTCH report (Robeson County Health Department, 2013) credited the collaboration between Duke University Medical Center and Southeastern Medical Center in reducing heart disease for AIs in Robeson County because of two life-care vehicles and a cardiac catheterization laboratory (Robeson County Health Department, 2013). As part of the University of North Carolina (UNC) Heart and Vascular Network, The University of North Carolina Physicians Network (UNCPN) opened cardiology services in Lumberton to ensure patients in this area have access to cardiovascular treatments (University of North Carolina Physicians Network, 2015). Although others have recognized the specific need for cardiovascular interventions in Robeson county and improving access for cardiovascular health, less invasive and less costly interventions are through preventative actions.

As of the February 8, 2016 report from the Department of Health and Human Services, Division of Health Service Regulations, hospitals licensed by the state of NC that serve the counties where many AI live include: Bladen (48 general beds), Columbus (154 general beds), Harnett (151 general beds), Sampson (116 general beds), and Scotland (97 general beds). Each of these counties has at least one free or income-based clinic. For example, there are five (5) free or income-based clinics in Bladen and Columbus Counties, ten (10) in Harnett, six (6) in Sampson and one (1) in Scotland (FreeClinics.com, 2016). This is a large geographic area with no public transportation to any of these county hospitals or clinics.

Determinants of Health

What makes a person healthy – or ill? There is no single answer. One's state of health or 'illness' is a combination of many health factors that many organizations and professionals have sought to find.

As early as 1968 when The Institute for the Future (ITF) began to research policy and study populations in order to predict future health care needs, understanding health determinants became important. The ITF is an independent interdisciplinary international professional research group that analyzes health, public policy, and primary and secondary data to forecast future needs (The Institute for the Future, 2015). The ITF claimed that they were pioneers in using in-home ethnographic observations and interviews to understand hidden meanings of personal health ecologies and practices (The Institute for the Future, 2015). The ITF used these data to predict determinants of health. They (ITF) published in 2003, yet cited the Centers for Disease Control and Prevention (CDC), that from 2001 to 2010, the major health determinants would be access to care (10%), genetics (20%), environment (20%), and healthy behaviors (50%) (The Institute for the Future, 2003). This reflected the belief that the burden of disease was changing from infectious causes to health behaviors (The Institute for the Future, 2003).

Health is influenced by multiple factors. Health care and research is shifting from single track thinking to a more holistic approach. Health behaviors, conceivably, could include patients' choices or the decision making processes they use regarding when they

access and utilize health care. Research aimed at understanding how people make decisions is important for change, especially for AIs.

Surprisingly, the 2001 to 2010 determinants of health ignored the earlier inference of socioeconomic influences (The Institute for the Future, 2003). The published 2008 predictors did not list specific determinants of health, yet they listed six challenges including sustaining environment, transforming bodies and lifestyles, making information actionable, ensuring affordability and value, reinventing medical practices, and connecting work and health (The Institute for the Future, 2015). Perhaps additional publications can be expected regarding current determinants of health. The IFTF and the CDC are not the only institutes that address health determinants.

Building on the work of America's Health Rankings, for example, the County Health Rankings and Roadmaps (2015) included four distinct sections with specific items within each section to describe what makes a county healthy. These health factors included health behaviors (30%) (alcohol and drug use, diet and exercise, sexual activity, and tobacco use), clinical care (20%) (access to care and quality of care), social and economic factors (40%) (education, employment, income, family and social support, and community safety), and physical environment (10%) (air and water quality, housing and transit) (County Health Rankings and Roadmaps, 2015). Personal decision making was represented in the social factors as social capital. It is important to note that genetics and biology were not a part of the County Health Rankings. Although slightly different from the IFTF and the CDC, a holistic approach was still used to explain determinants of

health. A person's decision making process was included as an important factor in this model.

Without including specific percentages, the World Health Organization (WHO) (2015) described determinants of health as social and economic environment, physical environment, and a person's individual characteristics and behaviors. Surprisingly, the WHO (2015) stated that access and use of health care services had less of an impact on health outcomes than in their previously stated determinants. There was no specific explanation as to why access and utilization of services was now deemed less important by the WHO. Yet, they did include personal behaviors that could include decision making processes.

Influenced by the Social-Ecological Model (SEM), the US Department of Health and Human Services (2015), again without percentages, identified health determinants within the Healthy People 2020 document as policymaking (local, state, and federal) social factors thought of as social and physical determinants (educational and job opportunities, wages, healthful foods, social norms/attitudes, crime, social support, socioeconomic conditions, transportation, segregation, physical environment, schools, neighborhoods, housing, aesthetics), health services (lack of availability, cost, insurance coverage, language), individual behavior (diet, physical activity, alcohol/nicotine/other drug use, hygiene) and, finally, biology and genetics (age, sex, family history, inherited conditions). Clearly, there are many modes by which health and illness are influenced. The health factor or determinant of health that was common to these examples was that of social influence on personal behavior. For example, if healthy food was not available

or affordable, the personal decision to eat unhealthy may be due to social factors, not necessarily personal choice. People eat what is available or they starve. Their food intake then influences their overall health. To understand which of these many social factors influence personal behaviors, we must ask the people. Then, we must act to reduce the factors that result in poor decision making in order to help them make more healthy decisions. But first, we must understand the decision making processes that influence health, including how AIs experience illness. This study assisted in that goal.

Need for the Study

The local, state and federal statistics support the understanding that AIs in North Carolina have poor health outcomes. Likewise, prevention of illness and promotion of health for this vulnerable population is vital to the state and national economy. The nation is slowly recovering from an economic recession and now holds health care providers accountable for efficient and effective health care. North Carolina did not accept the ACA Medicaid extension option, leaving many citizens without health care insurance, ultimately leaving them without timely, quality treatment or opportunities for preventive health screening. As a result, due to disabilities from chronic illnesses, personal and family burden from illness, the high cost of health care treatment for chronic illnesses, and a national debt in the trillions, research was needed to understand how to *best* reach and care for the AI community. Establishing health partnerships with AIs must begin with an in-depth understanding of what the AIs believe to be true about illness and what factors affect how they seek and use the health care system and its providers. Nursing is guided by holistic understanding and care, which parallels the basic

requirement for culturally competent health care. Thus, nursing research devoted to understanding AIs' perception of illness and factors that influence access and utilization of health care was essential. This research was critical to guide change that could ultimately lead to improvement in their health outcomes.

This qualitative research used focused ethnography methodology to guide the study and the SEM to situate inductive analysis findings into context. Focused ethnography methodology will be discussed in detail in chapter 3. In the following section the SEM is discussed.

Social-Ecological Model (SEM)

The SEM is a mixture of behavioral science theorist Bronfenbrenner's Ecological Systems Theory, McLeroy's Ecological Model of Health Behaviors and Stokols' Social Ecology Model of Health Promotion (Victorian Curriculum and Assessment Authority, 2014). This model is widely used in public health research, mostly because it recognizes the importance of the interaction between multiple levels of influence between an individual and his family, community, and other organizations (Baker & Sgoutas-Emch, 2014). Before the early 1980s, health research was primarily focused on an individual's choices and lifestyle (Simons-Morton, McLeroy & Wendel, 2012). Recently, Bronfenbrenner, a developmental psychologist, began the initiative to view an individual's choices from a broader lens with his model *The Ecology of Human Development* (Simons-Morton et al., 2012). Specifically, his theory redefined individuals' choices as being greatly influenced by previous experiences and significant relationships within the family and community (Simons-Morton et al., 2012).

Bronfenbrenner illustrated his idea with a systems level approach using terms like micro (interpersonal), meso (organizational), exo (community), and macro (cultural) systems to identify the levels in which interaction and influence evolve (Simons-Morton et al., 2012). The model continues to change with time as well. For example, in the late 1990s, McLeroy and colleagues edited Bronfenbrenner's original model and began to address how an individual's decisions could influence chronic health (Simons-Morton et al., 2012). Next, Stokols' 1996 edition of the *Social Ecology of Health Promotions* influenced the portion of the model that identifies places or targets for health behavior interventions (Golden, McLeroy, Green, Earp, & Lieberman, 2015; Simons-Morton et al., 2012).

In the 2003 Institute of Medicine's (IOM) report *Who Will Keep the Public Healthy*, the SEM became recognized as a fundamental element and concept for public health theory and practice (Simons-Morton et al., 2012). The SEM serves as the framework for many research projects funded through the National Institutes of Health population disparities centers (Simons-Morton et al., 2012).

Even as the SEM evolved, its overall structure remained the same. The design is illustrated as a set of nested structures, each inside the next with the inner layer identified as the microsystem, followed by mesosystem, exosystem and finally the macrosystem (Reifsnider, Gallagher, & Forgione, 2005). Many studies (Baker & Sgoutas-Emch, 2014; Boutin-Foster, Scott, Melendez, Rodriguez, Ramou, Kanna, & Michelen, 2013; Gregory, Wilson, Duncan, Turnbull, Cole, & Young, 2011; Nuss, William, Hayden, & Huard, 2012) used the constructs a) individual, b) interpersonal-level, c) organizational, d)

community, and e) policy as a label for the multiple levels. The interaction between the layers is termed reciprocal determinism from the Social Cognitive Theory (SCT) (Bandura, 2001; Bandura, 2004; Simons-Morton et al., 2012). There are several models available identifying the constructs using slightly different names condensing the interpersonal and the organizational and/or the community levels.

Through consultation with professors at Deakin University and the University of Ballarat, the Victorian Curriculum and Assessment Authority (VCAA) (2014) offered a slightly different guide using the social-ecological framework. Key constructs include (a) individual, (b) social environment, (c) physical environment, and (d) policy. Another option is what Cassel (2010) identifies as the Social-Ecological Model of Health where an individual's health is influenced by biological and genetic factors, social and family relationships, environmental predicaments, and finally, social and economic trends. He (Cassel, 2010) streamlined the constructs into biological, cultural, and socioeconomic/political variables. Regardless of the option selected, overall the concepts with the SEM remain the same – relationships and influences at multiple levels affect health care decision making processes and ultimately the decision.

Conceptual Definitions

From innermost layer to outmost layer, the constructs include 1) microsystem/individual, 2) mesosystem/social environment, 3) exosystem/physical environment, and 4) macrosystem/policy (Reifsnider et al., 2005; VCAA, 2014). Figure 1 illustrates the layers of relationships that influence behaviors. The social environment addresses cultural and society relationships (VCAA, 2014). The physical environment

includes natural and man-made environments (VCAA, 2014). Lastly, policy refers to public laws, regulatory issues or legislation (VCAA, 2014). Constructs and variables within the Social-Ecological Model used in this option include

- Microsystem/Individual with variables to include age, sex, level of education, socioeconomic status, employment status, knowledge, attitudes, and behaviors;
- Mesosystem/Social environment with variables to include family support, peers, institutions and organizations (school, workplace and community), access to social support, influence of health professionals, cultural background, and socioeconomic status of the community;
- Exosystem/Physical environment with variables to include access to facilities, perceived qualities of the facilities, perceived quality of natural environment (land, air, and water) safety (crime rates, traffic near facilities), weather, community design, density of housing or land use, and public transportation;
- Macrosystem/Policy with variables to include community planning policies, transportation policies, health policies, environmental policies, workplace policies, and funding policies (VCAA, 2014, p. 5).

The broad concepts of microsystem/individual, mesosystem/social environment, and exosystem/physical environment will be operationalized. This will allow for the themes derived from the inductive analysis to be viewed through the SEM lens.

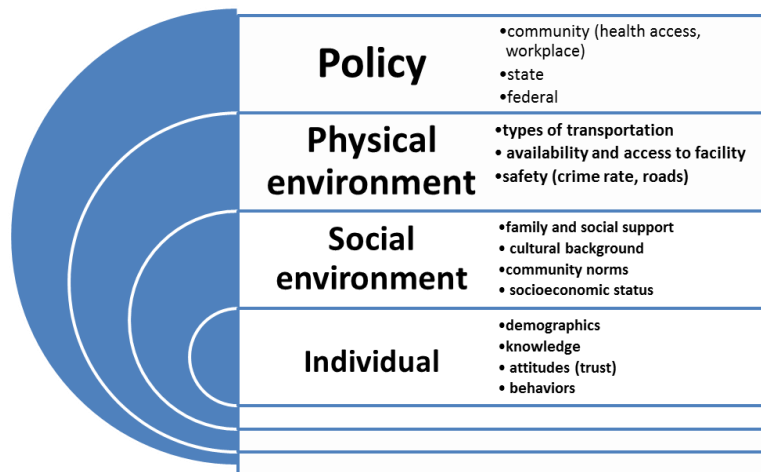


Figure 1. Social-Ecological Model (Adapted from the Victorian Curriculum and Assessment Authority (VCAA) 2014).

Operational Definitions

- **Microsystem/Individual.** Age, sex, level of education, socioeconomic status, and employment status were measured with a principal investigator designed demographic tool (see Appendix A). Knowledge and attitudes (trust) regarding the experiences of illness and the decision making process for access and utilization of health care services were obtained through focus groups (for questions see Appendix B) and individual semi-structured interviews (for questions see Appendix C). During the interviews and focus groups, leading questions such as “How do you feel about your current health?”; “What do you consider to be ‘good health’?” and “What do you consider to be ‘poor health’?” were asked. Additional questions included “When was the last time you felt really sick?” with a follow up question of “Can you tell me more about that?” Another leading question was “How do

you feel about going to the clinic/hospital department?” with a follow up question “What, if anything, do you wish could be different?” Trust for health care providers was examined with a leading question “How do you feel about your health care provider?” and a follow up question “Can you tell me about how you feel about trust and trusting in your provider?”

- Mesosystem/Social environment. Family and social support, cultural backgrounds, and community norms were obtained with semi-structured interviews and focus groups. One leading question was, “How do you make the decision when to go see a health care provider?” Follow up questions were: “Can you tell me the last time you did this?” and “How did you decide where to go?”; “What happened next?” and “Who else, if anyone, did you talk to about it?”. If they did not seek care, follow up questions were “Can you tell me more about why you chose not to?” and “What, if anything, would you like to be different next time?” The socioeconomic status of the community was measured with publically available state and county statistical data.
- Exosystem/Physical environment (types of transportation, crime rate, road safety) were measured with state and county public information. Access to facilities and types of transportation were asked qualitatively during focus groups and semi-structured interviews. Questions included “What, if anything, gets in the way of your using the clinic/hospital/health department?” with a follow up question “What about things like insurance, transportation, traveling/time, safety, or work hours?”

- Macrosystem/Policy was not measured in this study. Yet, policies were examined through analysis of current federal, state and county policies and potential needs for policy change may be a part of recommendations based on study findings.

To further demonstrate the interaction between the SEM layers, leading questions such as “If someone asked you for advice on where to go for health care, what might you tell them?”; “If someone asked you for advice on who to see related to health care, what might you tell them?”; and “Why do you think that some people go to the clinic while others don’t go?” were asked. A final question was “Is there something else you’d like to add?”

Research Questions

1. How do American Indians in southeastern NC describe illness or being ill?
2. What do American Indians in southeastern NC consider as important factors in their decision making process for accessing health care?
3. What do American Indians in southeastern NC consider as important factors in their decision making process for choosing to utilize health care services?

Assumptions

There is an interrelationship among health determinants that affect health outcomes. There is an interrelationship among social factors and the individual that influences the perception of illness. There is an interrelationship among social factors, the environment, and personal health seeking behaviors that influence decision making processes in accessing and using health care services.

Definitions

For clarity, definitions used throughout the study are briefly explained in alphabetical order.

Access to Health Care

Access to health services (AHS) is addressed in the Healthy People (HP) 2020 goals. The overarching goal is to improve access to comprehensive, quality health care services by focusing on four components to include coverage, services, timeliness, and workforce (US Department of Health and Human Services, Healthy People 2020, 2015). For the purpose of this research, access to health care is noted if services are available, affordable, physically accessible, and culturally acceptable.

American Indian/Native American

In many areas, the terms American Indian and Native American are used interchangeably. Yellow Bird (2006) rejects both terms and prefers indigenous or First Nation's people; he believes American Indian and Native American terms to be inaccurate and oppressive. Walbert's (2009) literature review explained differences between the terms in *American Indian vs. Native American: A note on terminology*. Walbert (2009) indicated that in many government and legal documents for federal tribes the term American Indian was and is still used today, whereas in many state-only recognized tribes the term Native American is used. In North Carolina, the term American Indian is used often by the Commission of Indian Affairs, Advisory Council on Indian Education, and American Indian studies (Walbert, 2009).

When known, the specific tribal name or the term used in the area is the best term to use (Walbert, 2009; Yellow Bird, 2006). This work did not focus on or inquire about any specific tribe in southeastern NC. Therefore, for the purpose of this research, with the exception of authors whose work used the term Native American, the term American Indian was used. Furthermore, for this research, American Indians are any persons self-identifying as American Indian.

Chronic Illness

A chronic illness is any disorder that is long-lasting that can be controlled but not cured (The Center for Managing Chronic Diseases (CMCD), 2015). Chronic illnesses may affect physical, emotional, intellectual, social or spiritual functioning (Merriam-Webster Online Dictionary, 2015).

Culture

For the purpose of this research, culture is “a set of shared and socially transmitted ideas about the world that are passed down from generation to generation” (Daher, 2012, p. 66). Cultural values and beliefs give meaning to illness, wellness, and disease within both illness and wellness. Cultural beliefs are based on cultural values and guide human behavior in health and illness and influence how a culture defines health and illness as well as symptom seeking behaviors (Munoz & Luckman, 2005; Peercy, Gray, Thurman, & Plested, 2010; Rhoades, Al-Oballi Kridli, & Penprase, 2011; Starr, 2008; Streetman, 2011). Kashima and Gelfand (in press) explain that anthropology was first credited with defining culture and quotes Edward Burnett Tylor’s 1871 work from “The Science of Culture” in *Primitive Culture* with “Culture or Civilization, taken in its

wide ethnographic sense, is that complex whole which includes knowledge, belief, art, morals, law, custom, and any other capabilities and habits acquired by man as a member of society (p. 3).”

Cultural Competence/Sensitive Care

Cultural and linguistic competence is a set of compatible behaviors, attitudes, and policies that unite in a system, agency, or among professionals that enables effective work in cross-cultural circumstances and environments (US Department of Health and Human Services Office of Minority Health, 2015).

Determinants of Health

Biological, personal, social, economic, and environmental factors and their interrelationships are determinates of health and are captured under broad categories of policy making, social factors, health services, individual behaviors, and biology and genetics (US Department of Health and Human Services, Healthy People 2020, 2015).

Disease

Disease is the presence of objectively measurable symptoms based on a medical professional’s evaluation and requires medical intervention (National Center for Cultural Competence, Georgetown University, 2015; May, 1993).

Health

Medical sociologists define health as the capacity to perform his or her role in society (Parsons, 1972). This study will define health as the World Health Organization (WHO) defines health. The WHO defines health as “a complete state of physical, mental, and social well-being, and not merely the absence of disease or infirmity” (World

Health Organization. 1948, Official Records of the World Health Organization, no. 2, p. 100).

Health Care Services

Health services are any resource that contributes to improving health, or to the process of diagnoses, treatments, or restoration of health to the sick (WHO, 2015).

Health System

Health systems are defined in two ways, a) all activities to promote, restore, or maintain health to include more than medical diagnosing and treatment, and b) the collaboration of people, institutions and resources required to improve health (WHO, 2015).

Health Disparities

For the purpose of this research, the US Department of Health and Human Services, Office of Minority Health, National Partnership for Action 2011 definition of health disparity as offered in Lavesit and Isaac (2013) will be used:

A particular type of health difference that is closely linked with social or economic disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater social and/or economic obstacles to health and/or a clean environment based on their racial or ethnic group; religion; socioeconomic status; gender, age, mental health, cognitive, sensory, or physical disability; sexual orientation; geographic location; or other characteristics historically linked to discrimination or exclusion (p. 14).

Illness

Illness is defined as any physical, spiritual, or emotional unhealthy state or condition of being unhealthy (Merriam-Webster Online Dictionary, 2015). Illness is

defined by a person's perception and evaluation of how he or she feels (National Center for Cultural Competence, Georgetown University, 2015). Illness may be defined culturally where disease may not be (Medical Anthropology, 2015).

Population Health

According to the Institute of Healthcare Improvement (IHI) (2015), population health means the health outcomes of an individual to include the distribution of outcomes within the group. Groups can be classified as nations, communities, ethnic groups, or any other defined group (IHI, 2015). Population health is focused on improving the health of the entire population of interest.

Federally vs. State-Recognized Tribes

A tribe is a group of people who live together and share language, culture, and history (Cambridge Dictionaries Online, 2015) sharing common territories or identifiable territories and kinship (Britannica Online Dictionary, 2015). Some anthropologists replace the word tribe with ethnic group (Britannica Online Dictionary, 2015).

Federally-recognized Tribes have treaty agreements with the US Federal Government and are considered a separate sovereign government. Thus, the government-to-government relationship. They are not bound by state laws and have the right and authority to regulate activities on their land. The US federal government is the trustee of their land and by treaty agreement is responsible for financial assistance for education, housing, health, and social welfare among other services (Bureau of Indian Affairs, 2015).

State-recognized Tribes and partially recognized federal tribes do not have a federal treaty agreement and are not considered a sovereign nation by the federal government. They are, however, recognized by their state and are allocated some funding for education, housing, health and social welfare from their state.

Utilization of Health Care

Simply, utilization is defined as to put to use (Merriam-Webster Online Dictionary, 2015). Utilization of health care can be defined as the outcome of an interaction between health providers and patients and measures the effects of realized access from a patient's perspective (Andersen, 1995; Gelberg, Andersen, & Leake, 2000). Others define utilization from a provider or payer's perspective as volume of services, medical treatments, or days in the hospital (CDC, 2015; US Census, Health and Nutrition, 2012). In this study we define utilization of health care from the patient's perspective to include, yet not be limited to actual health care provider visits, attempts for health care provider visits, and patient preferences for care to include health seeking behaviors, culturally appropriate care, perceived need for care, and satisfaction with care.

Chapter Summary

Most AIs in North Carolina live in rural areas and have limited access to primary health care. There is a growing incidence of chronic illnesses such as strokes, cardiovascular disease, and diabetes among the AI community. The cost of chronic illness has crippled this population physically and emotionally and caused undue financial hardship. The ACA has charged health care providers to create patient-provider partnerships to improve health outcomes for *all* citizens through the management of

population health. Establishing health partnerships with AIs must begin with an in-depth understanding of AI's beliefs about illness and factors that affect access and utilization of health care. Little, if any, research has been completed to evaluate the type of health care AIs in southeastern NC would access or use.

The purpose of this research was to understand factors that affect the decision making process to access and use health care among AIs in southeastern NC. This research was critical to direct change. Focused ethnography was used to understand the experience of illness, and factors that affect the decision making process to access and use health care among AIs in southeastern NC. The Social-Ecological Model was used to situate the inductive analysis into context. Chapter 2 will review the state of the science related to NC AIs and address the gaps in the literature for the state recognized tribes in NC.

CHAPTER II

LITERATURE REVIEW

Most American Indians (AI) in North Carolina (NC) live in rural areas with limited access to primary health care, where chronic illness is a growing concern. Subsequently, the emotional and physical costs of illnesses have caused undue hardships. The Patient Protection and Affordable Care Act (ACA) has imposed requirements on health care providers to create patient-provider partnerships to improve health outcomes. Establishing partnerships with AIs will require an in-depth understanding of AI's beliefs about illness and factors that affect their access to and utilization of health care. The purpose of this study was to understand the perceptions and experiences of illness and how American Indians in southeastern NC describe their decision making processes with regard to access and utilization of health care. Understanding their beliefs could open conversations and provide motivations for health care providers and policy makers to develop disease prevention and health promotion programs that are specific for AI population health management. This chapter will review the state of the science and the gaps in the literature related to perception of illness and access and utilization of health care for AIs. In search of a comprehensive, yet clear, understanding of the meaning of illness and health care decision making processes for AIs in southeastern NC, a literature review to examine illness and the relationship of health determinants and access and utilization of health care was explored.

It is important to note that the majority of research related to AIs has been conducted with persons living west of the Mississippi River or with federally recognized AIs living outside the reservation, leaving research for state recognized AIs in NC unexamined in many health areas. Research regarding specific illnesses, primarily cardiovascular and diabetes-related, to include risk factors, consequences, and interventions can be easily found for those in federal tribes. There has been, also, extensive documentation on federal tribal policies related to health care. The reasons for less knowledge development related to the state recognized tribes in NC are unknown. Yet, reasons could be related to NC AI's fear of participating, methods of conducted research, lack of researchers' interest or funding, or the remote locations where many of these persons reside. Following is a review of the empirical literature for American Indians.

Overview of the Literature

Most of the research specific for AIs in southeastern NC has been designed to examine the elderly and children focusing primarily on diabetes, cardiac conditions, nutrition, cancer screening, food access and access to oral health care. Using national, state, and local research and statistical data, following is a review of the literature related to illness, access to health care, utilization of health care by American Indians, particularly for those living in southeastern NC followed by current federal, state and county goals.

Defining Illness

Each culture manifest unique behaviors. Each culture dictates acceptable behavior within that group (Munoz & Luckman, 2005). Cultural values and beliefs give meaning to illness, wellness, and disease. Cultural beliefs are based on cultural values and guide human behavior in health and illness and influence how a culture defines health and illness as well as symptoms for which individuals seek health care (Munoz & Luckman, 2005; Rhoades, Al-Oballi Kridli, & Penprase, 2011; Starr, 2008; Streetman, 2011) and have been studied with AI populations in both the federal and in NC state tribes.

Although studies are not found specifically for defining illness, studies are available focusing on cultural beliefs and health behaviors. In 1998, the Rural Health and Nutrition Study, a three year ethnographic study began in central North Carolina focused on Native Americans (NA) and African Americans (AA). Bell, Quandt, Arcury, McDonald, and Vitolins (2000) examined health behaviors of rural white, AA and NA elders in search of modifiable behaviors that could reduce chronic illnesses in rural older people in NC. This study reported a high degree of self-reported preventive behaviors by older adults in the three ethnic groups to include taking nutritional supplements, having annual blood pressure checks and limiting alcohol use. Additionally, this study found a divide between the perception of performing preventive behaviors and actually performing the behaviors. In this study, the reported dietary intake compared to the reported compliance with dietary standard guidelines were given as examples of the divide between perception of preventive behaviors and actual behavior. Other studies include positive correlations between cultural-contextual beliefs and health behaviors

(Kumanyika, Taylor, Sonya, Lassiter, Lassiter, Morssink, & Renzaho, 2012; Jaremo & Aman, 2011; Smyer & Clark, 2011). For example, Smyer and Clark (2011) focused on elder abuse in a federally recognized AI community. They describe how AIs are family-centered and depend on them for supportive care, to include during their older years of life. Because of the increased demands and stress of chronic illnesses that many times accompany old age, the caregivers become overwhelmed. Familial responsibilities often contribute to elder abuse (Smyer & Clark, 2011).

Cultural beliefs and cultural health perception affect disease awareness as well as preventive measures and behaviors (Aroian, Peters, & Waser, 2012; Cavanaugh, Taylor, Keim, Clutter, & Geraghty, 2008; Daher, 2012). For example, Cavanaugh and colleagues (2008) studied cultural perceptions of health and diabetes among AI males in Oklahoma. They found that men who engaged in positive behaviors such as a healthy diet and exercise considered themselves healthier than those who did not.

In some studies, health beliefs, attitudes, behavior and cultural beliefs influenced prevention information-seeking behaviors (Broome & Broome, 2007; Jaremo & Aman, 2011; Lim, Baik, & Ashing-Giwa, 2012; Odegina et al., 2011; Rhoades et al., 2011). For example, Broome and Broome (2007) explained that AIs living on reservations believed that diseases were caused by immoral behaviors or by negative spirits. Treatment may impede any life lesson. Thus, health seeking behavior in traditional western medicine may not occur. Yet, they may seek AI traditional healers to restore balance through herbs, ointments, teas, and salves. Unfortunately, this study did not include state recognized AIs. Messer, Steckler, and Dignan (1999) studied early detection of cervical

cancer among AI Cherokee and Lumbee women in North Carolina. They found two cultural factors or categories that contributed to health seeking behaviors. The Cherokee women sought health care when it was supported or encouraged by the tribal government. The Lumbee women sought preventive screening with the community supported the effort. Many women do not seek health care if they believed it is an invasion of their privacy or if they believed that they are not sick. These studies did not identify or define illness or how these cultural behaviors contributed to the decision making processes of accessing and using health care for American Indians.

Zhao, Esposito, and Wang (2010) and Jaremo and Aman (2011) reported positive relationships between cultural beliefs regarding illness and the effects of health practices on wellness with people who have health-seeking behaviors. For example, Arman and Jaremo's (2011) study suggested that cultural beliefs could either facilitate or constrain health behaviors. In their study, participants in Sweden believed that the offensive treatment and mistrust in government agencies had caused their poor health. Others believed that illness was bad luck and did not see the need for wellness practices. There was also a positive relationship between cultural barriers in American Indian cultures and health consequences (Gibson & Watkins, 2011). Edwards (2005) stated that the lack of cultural competency in the delivery of health care had contributed to poor survival rates and increased incidence of cancer rates among non-white Americans. Cultural issues related to AIs and their behaviors have been studied in NC, yet in a limited way. NC American Indians' perception and experiences of illness or, if their definition of illness

aids in the decision making process of accessing and using health care have not been studied.

An AI physician named Mehl-Madrona (1997) wrote “All illness is an illness of the spirit that manifests itself in the body, mind and emotions, and we all carry within our souls the capacity to heal ourselves” (p. 17). The National Library of Medicine at the National Institute of Health presents an interactive exhibit called *Native voices: Native peoples’ concepts of health and illness* to explore the concepts of health and illness for Native Americans (Lindberg, 2013).

According to Lindberg (2013) Native people believe that people are responsible for their own behavior and health and at the center of health and happiness are the community and tribe. Native people also blend physical reality with spirituality, most likely in part due to their respect for nature and belief in a Supreme Being (Lindberg, 2013). A common theme of frustration related to the unfair treatment towards Native people emerged (Lindberg, 2013). In addition to unfair treatment, the Native Americans credit the industrial civilizations, and the efforts to eradicate Native pride as contributors to poor health and limited recovery from illness (Lindberg, 2013). The data from this presentation was from federally recognized tribes to include the southeastern region (National Library of Medicine, 2015). There was no representation from state recognized tribes in the southeastern region of the United States.

Although the exhibit’s title spoke of concepts of illness and health, there were no clear definitions of illness or health for Native Americans. The interviews did, however, suggest that some Native Americans believed that illness was an imbalance of nature or

some imbalance in their own life, or even a punishment. In addition, some AIs were Christians and believed the Christian views of illness and health (National Library of Medicine, 2015). What Christians believe or do not believe in regard to health or illness were not identified in this exhibit. According to the Native Proverbs 31 Health Project, AIs in eastern NC are mostly of the Protestant faith, Christians, and believe in faith-based healing (Kimes, Golden, Maynor, Spangler, & Bell, 2014).

Definitions of health and unhealthiness for AIs with mental illness were found in a grounded theory study with non-North Carolina American Indians (Yurkovich & Lattergrass, 2008). Yurkovich and Lattergrass (2008) identified that for those American Indians the meaning of health was having a personal sense of balance and harmony between a person and the universe, being in control of the spiritual, cognitive, emotional, and physical being which was achieved through a process of self-awareness, honesty, appropriate behaviors, and having a purpose or job. An imbalance in the physical, mental, social, or emotional produced negative energy or a state of being unhealthy (Yurkovich & Lattergrass, 2008). There was not a clear definition of illness within this study.

Literature associated with defining illness or disease for North Carolina American Indian tribes was limited. Some literature supported that many American Indians believed that illness and dying were pure processes of living and that they believed in natural healing (Cavanaugh et al., 2008; Daher, 2012; Smyer & Clark, 2011), which may have contributed to issues and trends of their not seeking what was thought of as traditional western medicine or health care. Specific health, illness and health seeking

behaviors studies have primarily been conducted among American Indians who live on reservations (Munoz & Luckman, 2005; Perry & Hoffman, 2010; Rhoades et al., 2011; Streetman, 2011) or those who have moved from the reservation to an urban community (Cavanaugh et al., 2008). There was no literature that supported that there may have been a difference in how the state tribes view illness compared to the federally recognized American Indians. No literature was found that defined or described illness or what it meant to be ill for AIs in southeastern NC.

Jacobs, Kemppainen, Taylor and Hadsell (2014) compared the personal beliefs about the causes and meaning of having diabetes to medication adherence for the Lumbee tribe in NC in their mixed methods, descriptive, correlational study. They used the revised Illness Perceptions Questionnaire (IRQ-R) to assess the perception of illness using Leventhal's illness representation model. This model included identity (the symptoms associated with the illness), cause, consequences, and cure-control (control or recovery). They also used the Timeline/Acute chronic subscale to measure beliefs about the duration and the Timeline/Cyclical subscale to measure personal beliefs about the variability and unpredictability course of diabetes. They found that even though the participants viewed diabetes as a long lasting condition, the participants had moderate understanding of the variability and unpredictability associated with having diabetes.

Additionally, they found by examining the Consequence subscale and Personal Control subscale that participants believed that diabetes was a serious illness and could be influenced by personal behaviors. By examining responses to open-ended questions, they found two themes that represented the cause of illnesses: genetics and lifestyle

practices. Lifestyle practices included drinking sugary drinks, lack of exercise, and lack of healthy diets. This study did not correlate cultural behaviors or beliefs to diabetes. This study was exclusively for Lumbee AIs living in rural Southeastern, NC, yet it did not define illness for these participants or inquire about decision making processes to seek health care. Although Fleischhacker et al.'s (2012a) NC study on the American Indian Healthy Eating Project and access to healthy foods for AIs did not include in their research purpose or questions their intent to study AI perceptions of illness, they reported that many AIs believe that illness and dying were pure processes of living.

In Nance-Floyd's (2015) unpublished work titled *Focused ethnography study to examine current health status of Native Americans in Eastern North Carolina*, unexpected findings regarding what illness meant to NC NAs emerged. These preliminary findings warrant further examination to understand the meaning of illness and the decision making processes for NAs living in southeastern NC regarding their access to and utilization of health care. The purpose of the 2014 study was to examine current health status as it related to cultural behaviors and current health care policies for Native Americans in eastern North Carolina. During semi-structured interviews and a focus group, the raw data from June 2014 included one participant stating,

For a person around here to consider themselves sick, they would have to have something like a cold, cold or flu and they would have to be in bed for like 2 days and feel like they couldn't physically do anything.

Another participant added,

I wasn't raised to go to the doctor. You go to the doctor when you're sick. You don't necessarily go for regular check-ups and those kinds of things. I do think that that is a little bit of a cultural thing. With my parent's being older and coming from the age group that they're in, they were raised you don't go to the doctor unless you're sick. We say sick – they're dying basically around here.

One participant said to another,

You know how you (*looking at the participant*) said cancer patients who go and their finally diagnosed with cancer so far into the stages sometimes stage 4 cancer. They can't do anything about that because they've waited so long. People around here they say – 'I'm not going to the doctor until I have to.' I've heard people say – 'you go to the hospital and then you die' (*many others in the focus group nod head in agreement*). That's what happens when you go to the hospital. They're afraid. That's the reason why they end up dying when they go but... But, they think that's what happens when you go to the hospital because you've waited so long.

Simply, understanding their perception of illness has not been studied for state recognized AIs in North Carolina. For better population outcomes, specifically for our AI citizens, understanding their beliefs about illness is a prerequisite for creating effective policies that could improve their health and well-being. Understanding their beliefs about illness may also shed light on how they decide to access and utilize health care services, making this research critical. To build better patient-provider relationships, and to build disease prevention and health promotion education and interventions, a deeper understanding of how NC AIs view illness was necessary and explored in this research.

Access to Health Care

The following section represents the literature related to access to health care.

Farmer, Bell, and Stark's (2005) study to explore cancer screening predictors and practices for the Lumbee Tribe found that participants with better education, over the age of 40, and who had healthy lifestyles typically had good access to health care. The definition of what was good access was not given in this study.

Another notable study was an intervention study that served all state recognized tribes in North Carolina and was designed to improve access to healthy foods (Fleishhacker et al., 2012a; Healthy, Native North Carolinians, 2013). In 2008, through the collaborative efforts of the North Carolina AI tribes, the Center for Health Promotion and Disease Prevention and the American Indian Center at the University of North Carolina at Chapel Hill (UNC) and through funding from the Robert Wood Johnson Foundation, the American Indian Healthy Eating Project began its five phase project (Fleischhacker et al., 2012a). The focus was to build partnerships and evidence necessary to improve access to healthy, affordable foods within the seven state recognized AI communities in NC. Additional partnerships included the NC commission of Indian Affairs and the NC American Indian Health Board (Fleischhacker et al., 2012a). For this study, the Eastern Band of Cherokees declined to participate because they had, at the time, an existing obesity prevention program. Fruitful strategies included Tools for Healthy Tribes, a toolkit to improve access to healthier affordable foods, for tribal policymakers and the community (Fleischhacker et al., 2012a; Healthy, Native North Carolinians, 2013).

Building on this work, the Healthy, Native North Carolinians (HNNC) study funded by the Kate B. Reynolds Charitable Trust was launched through the American Indian Center at UNC (Healthy, Native North Carolinians, 2013). It (HNNC) fostered healthier choices for the state recognized tribes and three urban Indian organizations in NC to promote self-determination and community change in order to promote health and prevention of chronic diseases (Healthy, Native North Carolinians, 2013). Urban Indian organizations are neither designated state nor federally recognized and were included in the HNNC (Healthy, Native North Carolinians, 2013). This study focused on tribal and rural food access. Although this study provided valuable information related to access and barriers to healthy food for the AI population in NC, it does not provide specifics for access to health care or decision making processes that this population uses.

There were limited studies that specifically examined access to health care for AIs in southeastern NC. One study examined access to oral health care, not to primary health care. Wells, Caplan, Strauss, Bell, and George (2010) studied access to oral health dental services for the Lumbee tribe in southeastern NC. The purpose of their study was to evaluate access, issues, knowledge, and quality of life related to oral health for this population (Wells et al., 2010). Wells and colleagues (2010) learned that there was a relationship between poor oral health and access to oral health care. Barriers to access oral health care included dental offices long distances from where the AIs lived, unaffordable expenses of travel even for those with dental insurance, cost of services, and the inability to locate a dentist in their geographic area (Wells et al., 2010). Two studies that were not specific to AIs, one from rural western NC (Arcury, Preisser, Gesler, &

Powers, 2005), and the other (Mueller, Ortega, Parker, Patil, Askenazi, 1999) from other rural US areas identified transportation as a major issue related to health care utilization. Yet, there was no mention of perceived or real access to health care, health practitioners or perception of trust in care providers for AIs in southeastern NC found. Neither was there mention of NC AIs definition of illness as it related to when, where and how health care is accessed. Understanding these aspects for AIs in NC was needed before change and improvements can begin.

Knowledge

Paskett et al. (2004) studying African American (AA), Native Americans, and white females in Robeson County added to Wells et al.'s (2010) study identifying that lack of knowledge about where to receive health screenings and health clinic location preferences were barriers to the access to health care. It was important to understand how AIs received knowledge about what was available to them and their decision making processes for accessing the available health care so that intervention regarding access and utilization could be made.

Lack of Providers

Another barrier in health care access for rural communities was lack of primary care providers (Jost, 2014; North, McElligot, Douglas, & Martin, 2012; Robeson County Health Department, 2013; Ziller, Lendarson, & Coburn, 2012). For example, the US Department of Health and Human Services recognizes Robeson County as a county of medically underserved and acknowledges the shortage of primary care providers using the Medically Underserved Areas/Population (MUAs/MUPs) score (43.70) and the

Health Professional Shortage Area (HPSA) score for primary care (16) (US Department of Health and Human Services, Shortage Designation, 2015). The Index of Medical Underservice (IMU) scale is used to establish MUA/MUP scores. The IMU scale is represented on a 0 (completely underserved) to 100 (best served) range. Any score 62 or less is designated as an MUA. The HPSA score is scored from 0 to 26. For the HPSA, the higher the number the more need (US Department of Health and Human Services, Shortage Designation, 2015).

The Kaiser Family Foundation (2015) found in the 2013 data that in North Carolina 26.5% of adults reported not having a personal doctor and the Robeson County State of the County's Health (SOTCH) (Robeson County Health Department, 2013) acknowledged the lack of providers for health care in its rural areas. North and colleagues (2012) infer that primary care physicians were paid less than specialty physicians and that primary care physicians lack the desire to go to rural settings to set up practice. Even with the educational payback system, many physicians do not remain in a rural area after they have served their required payback time. Participants in Nance-Floyd's (2015) unpublished study with NAs in eastern NC indicated that many of the contracted physicians that receive funding through the student loan reimbursement for time served program that has been used for underserved areas leave after their contract was completed in three years.

The Institute of Medicine (IOM) (2011) report, *The future of nursing: Leading change, advancing health*, indicated that nurses should practice to the full extent of their education and training and the IOM should remove barriers that inhibit such practice. In

2012, 32 states did not allow NPs and PAs the ability to practice within their full educational scope (Health Policy Brief, 2013). North Carolina continues to be one of these states. The lack of providers and lack of continuity in care could lead to lack of trust in the providers, which needed to be examined further.

Travel

Chan, Hart, and Goodman (2006) suggested that patients in rural areas may utilize health care less often because of the time it takes to travel. They studied patients in rural areas, including in NC, and determined that patients in rural areas traveled two to three times the distance than those from urban areas (Chan et al., 2006) compromising access, particularly for patients with limited income for travel. A participant in a qualitative pilot study of NAs in eastern NC (Nance-Floyd, 2015) revealed "...you've got the little old lady who don't drive, so how's she going to get there? ...But, someone on fixed income don't have that. They can't just jump up and go until they're real sick." Another participant added "Medicare does not (have transportation). And with Medicaid – you have to sign up and it only goes where it's going on Tuesday afternoons... but your doctor is not there on Tuesday afternoons."

In a study focused on access to healthy foods for AIs in NC, Fleischhacker and colleagues (2012a) found that many times the closest grocery store was 15 miles away from communities. They used the Global Positioning System (GPS) to determine food outlets and discovered that there were over 6000 miles of roads in the Lumbee Tribal area (Fleischhacker et al., 2012b). Considering there are 3005.63 miles by car from Wilmington, NC to Seattle, Washington (Distance Between Cities, 2015), 6000 miles is

an extraordinary distance to travel to access health care. Unaffordable travel has been found to be an obstacle for accessing health care for this group.

Eligibility of Services

Being a resident on an Indian reservation and *federal* tribal belonging have been important factors for accessing health care for American Indians. Indian Health Services (IHS) provides clinics to include dental, eye care, mental health, rehabilitation, health education, social services, pharmacy services, and home health care (US Federal Government, Indian Health Services, 2015). These clinics are governed by federal tribes with a goal to provide culturally sensitive care using federal funds for members of 566 federally recognized tribes and 33 urban programs (US Federal Government, Indian Health Services, 2015). Unfortunately, state recognized tribes do not have these clinics or access to these clinics. State and non-state recognized AIs resort to private pay or Medicaid for payment of their health care. Many AIs in southeastern NC do not qualify for Medicaid and remain uninsured. In Nance-Floyd's (2015) pilot study of NAs in eastern NC, individuals speak about the lack of Medicaid eligibility for Native Americans in Eastern NC. One participant said,

...we have a lot of people in our community who don't qualify for the Medicaid because they own their home...it's the fact that they tried to have something else....they say 'there's a piece of property down the road for sale and let me buy it and one of my children might put a house on that one day and they're be close by'.

Another added, "So, now you've got property in 2 locations automatically disqualifies you for Medicaid". One person said,

...I worked all my life and tried to have something and now I'm being penalized because I tried to have something. Because I tried to not be depended on the government, now I can't work a job and I can't get affordable health care coverage because may be I didn't retire from a job.

Another agreed by saying,

..., they ended up not getting benefits. They may have worked the job for 20 years but not qualify for retirement benefits. And now, they say – 'I worked all my life and I don't have anything – I'm penalized'.

Unfortunately, another option that some NAs used to access health care is the prison system. During the *Focused ethnography study to examine current health status of Native Americans in Eastern North Carolina* (Nance-Floyd, 2015), unpublished data revealed participants' conversation during a focus group related to how some NA accessed health care. One participant said,

We have people in this area who will tell you – who have been in the prison system – they don't like being there but - they'll go back to the prison system because it's the only way they're going to get health care.

Another said, "Yep, it's the only way they're going to get health care." Another added, "And an education." One person said, "And a roof over their head." While another added, "And three squares a day (meals)." After a pause, one participant said

What happens is they don't have a job, they don't have a place to lay their head, they don't know where their next meals coming from, they get depressed, they get suicidal, and they commit crimes.

When citizens feel the need to resort to crime to gain access to health care, new policies are needed. It is important to understand how decisions are made related to access to health care for this group. Without clarity, it will be difficult to develop sustainable public policies or successful interventions to assist in access to health care for this population.

Utilization of Health Care

There have been a few studies examining utilization of health care services for the AI population in NC. For example, in 2001, Bell and colleagues published data from the Evaluating Long-term Diabetes Self-management Among Elder Rural Adults, known as the ELDER study, with the purpose of examining primary and specialty medical care utilization of older diabetic patients in rural NC, specifically African Americans (n=220), Native Americans (n=181), and whites (n=297) (Bell et al., 2005). This study revealed high (greater than 95%) utilization of primary care for older adults with diabetes, with the exception of eye care 72 %; (lower utilization of this specialty care). African Americans were more likely to seek a podiatrist than NAs. There were no ethnic differences in utilizing cardiology or ophthalmology services. Their study confirmed national findings (CDC, 2015; The Institute for the Future, 2015; US Department of Health and Human Services Office of Minority Health, 2015) that showed relevant predictors of utilizing medical specialties in rural populations including higher socioeconomic status (SES), more formal education, greater diabetes medication use, and higher self-rated health (Bell et al., 2005). This study provided evidence that people with greater financial means seek medical specialty services more frequently (Bell et al., 2005; US Department of Health

and Human Services Office of Minority Health, 2015). However, the study acknowledged that the results did not indicate if utilization of services was for treatment or prevention (Bell et al., 2005). In additional work, Bell et al. (2000) examined health behaviors of older AAs and NAs in rural NC to include health care use. Although, these studies were foundational in providing empirical findings related to the utilization of health care services for the Native Americans in state recognized tribes in central NC, they focused on those with previously diagnosed diabetes, and did not include those with other chronic diseases or utilization of services for preventive efforts.

Other studies, such as one by Yurkovich, Hopkins (Lattergrass), and Rieke, (2012), used grounded theory methodology in search of health-seeking practices for AIs in federally recognized tribes diagnosed with mental health illnesses. Avoidant behaviors (chemical use/abuse, suicide attempts, not engaging in therapy, denial of symptoms and treatment needs, and leaving the reservation) were perceived as coping strategies for not seeking services. (Yurkovich et al., 2012). There was no study similar to this for state tribes in NC, and having information about this unique group could be useful in understanding their perception of illness and when and how they access health care. Having this information could support intervention development to improve health outcomes for this population and provide important support for policy changes to improve their care and health, as well.

As identified in the Social-Ecological Model (SEM), additional factors that influence utilization of health care are trust, perceived need, SES and demographic factors. Available literature related to these concepts among AIs is presented below.

Trust

In general, trust was one of the greatest deterrents for AIs seeking health care from non-American Indian providers. White leaders and health care professionals (Cavanaugh et al., 2008; Daher, 2012; Smyer & Clark, 2011) have contributed to issues and trends that have resulted in AIs choosing not to seek traditional health care or participate in opportunities to advance health care knowledge. In the beginning when America was taking shape, traumatic events created an environment of mistrust between the American Indians and the colonists, and between the AIs and the new American government. Broken treaties by the new government and environmental segregation were just some of the consequences for AIs. They wrongfully lost many rights and their land (Stoner et al., 2015). This led to mistrust that still exists today.

Stoner and colleagues (2015) argued that more culturally competent health care providers are needed to work with AIs. Edwards (2005) asserted that AIs did not access health care because provider relationships lack culturally competent perspectives. Bell et al. (2013) examined physician trust among rural older AA, AI, and white adults with diabetes in NC. They used the General Trust in Physician scale and reported higher scores in participants over the age of 75, those with less than three chronic illnesses, and those who engaged in regular exercise (Bell et al., 2013). There were no statistically significant differences in trust in physicians between AAs (34.6), NAs (34.9) and whites (34.5) with a standard deviation of 7.6 (Bell et al., 2013). Ultimately, patients followed their prescribed regimen when they trusted their physician. As valuable as these studies are, they did not indicate if trust is part of the decision making process that AIs use when

deciding when and if to seek health care services. Having this information will be critical to the development of interventions to better serve this population.

Several studies (Dochterman & Grace, 2001; Munoz & Luckmann, 2005) reported that Native American's orient themselves in the past rather than focusing on future needs of ensuring good health such as preventive care. Yet, in the mid-2000s, studies revealed (Bell et al., 2000; Bell et al., 2005; Farmer et al., 2005; Paskett et al., 2004) the willingness of NAs to seek health care. To better serve the health care needs of this population, it was important to understand their decision making processes when deciding when and if to access care for themselves or their family members.

Perceived Need

One study, by Farmer and colleagues (2005), designed to explore cancer screening predictors and practices for Lumbee Tribe members found that 89.3% of the participants had a private doctor and only 3.5% used traditional healers. Further they found that appropriate cancer screening rates were high (Pap smear - 99.3% of the women; mammogram - 86% of the women, reported self-breast exam - 84.6% of the women, and prostate screening - 60.4% for the men), and one half of the participants over age 50 reported having received colon cancer screening. This study also found that participants with better education, those over 40 years of age, and those reporting healthy lifestyle behaviors with good access to health care frequent medical services more often (Farmer et al., 2005). Studies (Dignan et al., 1998; Farmer et al., 2005; Paskett et al., 2004) also revealed the willingness of Lumbee tribal members to seek health screening. Interestingly, Farmer and colleagues (2005) identified a paradox in their results. Nearly

90% of their study participants reported having a private doctor in an area that has been known to be medically underserved (Robeson County Health Department, 2013). Thus, since some NAs do access health care as evidenced in these studies, it appears that some NAs perceive the need to seek health care, at least for some health concerns.

Socioeconomic Status and Demographic Factors

Recently, Spleen, Lengerich, Camacho, and Vanderpool (2014) used Health Information Trends Survey (HINTS) data to estimate health care avoidance at a national level (n= 6,714). After controlling for confounders, they refuted previous studies that indicated that race and income were indicators of avoidance of health care utilization. Their study, however, did not include AIs as a specific ethnic category. It may be that their categories “other/multirace” or “unknown” included NAs. It did, however, provide information about utilization of health care and services to mostly non-American Indians that could be used later as a comparison. Spleen and colleagues (2014) found that one third of their participants did not seek a health provider even when they felt they should, and they identified three health avoidance patterns: sociodemographic, personal health and patient-provider. More specifically, they found that males, younger age groups, and those without health care insurance were more likely to avoid seeking health care. They added that lack of confidence or trust in the provider and poor provider rapport were associated with health care avoidance. They recommended that qualitative research methods were needed to further clarify the relationship particularly those between providers and patients with health care avoidance behaviors. Utilization of health care services has not been studied adequately for AIs, particularly for those in NC. Research

was needed to understand how AIs make decisions on when and how to utilize health care so that this information can be used to guide the design of interventions and strategies for helping to decrease the unfair burden this group faces with regard to health disparities.

Federal, State, and County Goals

Federal

Access to health services (AHS) for all Americans was addressed in the Healthy People (HP) 2020 goals. The overarching goal is to improve access to comprehensive, quality health care services while focusing on the four components: coverage, services, timeliness, and workforce (US Department of Health and Human Services, Healthy People 2020, 2015). American Indians are one of the groups facing disparities in health. Barriers to access are lack of available health care or providers, high costs, and lack of insurance coverage which had led to unmet health needs, inappropriate care, and avoidable hospitalizations (US Department of Health and Human Services, Healthy People 2020, 2015). There are nine major categories and twenty-three goals under the major objectives, none of which are specific to AIs, a group greatly affected by disparities in their health and in the health care they receive.

State

Healthy North Carolina 2020 has objectives addressing topics including tobacco use, physical activity and nutrition, injury and violence, maternal and infant health, sexually transmitted diseases and unintended pregnancy, substance abuse, mental health, oral health, environmental health, infectious diseases and foodborne illnesses, social

determinants of health, and chronic disease (North Carolina Institute of Medicine, 2011). Healthy North Carolina 2020 acknowledges the morbidities and mortalities that chronic diseases such as cardiovascular disease, diabetes, and colorectal cancer have had, and their vast impact on African Americans, including their staggering negative outcomes associated with these chronic diseases compared to whites (North Carolina Institute of Medicine, 2011). There was no mention of AIs in the report. Public policy strategies to reduce chronic illnesses in NC included community grants promoting physical activity and healthy eating, community wide obesity prevention, and funding for school-based and school-linked health services (North Carolina Institute of Medicine, 2011). Other than school-based health services imbedded within chronic illness care, access to health care were not addressed at the state level for AIs for any group. American Indians, especially those in eastern NC with high mortality and morbidities related to chronic illnesses, are in need of state goals and public policies to address access to health care for this vulnerable population.

Southeastern NC

Based on evidence from the 2013 SOTCH report and the 2011 Community Health Assessment, for the next several years Robeson County will focus on obesity prevention and substance misuse and abuse to include prescription drugs, tobacco, and alcohol (Robeson County Health Department, 2013). In 2013, the Community Transformation Grant Project (CTGP) and Girls on the Run/Girl on Track grant (GOTR) were the leading interventions to address the obesity problem in Robeson County (Robeson County Health Department, 2013). There were no specific interventions or grants listed in the Robeson

County SOTCH report related to how substance misuse/abuse will be addressed. The Robeson County SOTCH report did, however, identify substance misuse/abuse as an area of concern. The report reflected the need to continue to identify and create specific policies and interventions aimed at reducing disparities (Robeson County Health Department, 2013) which are believed to be important to improve the health of the people in Robeson County.

For Scotland County, the 2014 SOTCH report indicated that hypertension, diabetes, obesity, heart disease and cancer were their greatest health concerns (Scotland County Health Department, 2014). They indicated that they plan to continue their Community Action Plans to address these chronic illnesses to include Fitness Trails, Farmer's Fresh Markets, Scotland Place Senior Center and other innovations. In the report Scotland County offered specific suggestions to community members regarding how to get involved to encourage wellness and improve the health of persons in the county. For example, Scotland County encouraged businesses and industries to initiate personal wellness programs for employees.

Columbus County's 2015 SOTCH report identified chronic illnesses, drug/alcohol abuse, and obesity as their top three health concerns (Columbus County Health Department, 2015). In the report, it stated that 21% of the residents in Columbus county were uninsured. Yet, the action plan for the county did not include access to health care – only access to healthy food, promotion of healthy eating and exercise initiatives, and the recommendation of the provision of chronic disease and diabetes management programs. Columbus County has joined in a partnership with Wake Forest University to develop

strategies to reduce the burden of prescription drug misuse in the county (Columbus County Health Department, 2015). Understanding how AIs describe illness and how they make decisions to access health care or not has not been addressed at the county level in some of the poorer counties in southeastern NC.

Federal health goals embraced access to health care within Healthy People 2020 goals. NC state goals did not address access to health care. Yet, they did address chronic illnesses. There were no specific federal or state goals regarding access to health care that are specific for AIs. AIs were not mentioned in the health goals for NC. Several of the southeastern counties are focused on preventive measures for obesity and substance misuse and abuse of prescription drugs, tobacco, and alcohol. Yet, understanding how AIs experience illness or how they make decisions to access health care or not has not been addressed at the federal, state, or county level.

Gaps in the Literature

Available literature offered great insights into cultural and behavioral beliefs associated with chronic illnesses among AIs and described interventions that have been designed and tested to promote healthy eating and exercise (Bell et al., 2005; Bell et al., 2013; Dignan et al., 1998; Farmer et al., 2005; Fleischhacker et al., 2012a; Jacobs et al., 2014; Paskett et al., 2004; Stoner et al., 2015). Findings from these studies have been employed in building successful behavioral intervention programs. Although potentially vital to the overall health and health improvement of AIs, little effort has been devoted to how American Indians in NC describe or define illness or how they make decisions to access or utilize health care.

Addressing a Gap in the Literature

While it is clear that health care for American Indians is inadequate, what is not clear is – why? Nurse researchers and health care providers focus their practices on improving the health of individuals, groups, and populations. To do so, the individual, group or population must be understood in order to design effective strategies to address health care needs. Over the past ten years, research funding has increased for studies targeting vulnerable populations, yet nursing research focused on state recognized AIs is rare. Most research associated with AIs emanates from public health, medicine or a multidisciplinary approach. Nursing is guided by holistic understanding focused on building a trusting patient-nurse relationship that parallels several of the needs for American Indians. Nurses and AIs could be described as people who are anchored in trusting relationships and having the ability to see beyond traditional medicine for total healing. Research with American Indians has gained momentum and attention. Qualitative inquiry may foster the relationship between researchers and AIs and aid in the understanding of persons from this unique group. It is important to understand how they perceive illness and the decision making processes they use related to how, when and where they seek health care. This study may assist in providing foundation elements for future intervention design and testing and policy change to better manage the health for this population.

Chapter Summary

Although there are several AI tribes located in NC, research specific for this AI population has largely been limited compared to research for AIs who live west of the

Mississippi River. Research for the AIs in southeastern NC has been designed primarily to examine the elderly and children focusing on chronic disease, particularly cardiac conditions and diabetes, cultural health perceptions that affect disease awareness, and inquiry related to preventive measures in nutrition, cancer screening, and access to healthy food and oral health care. Yet, these studies did not explore illness or how behaviors contribute to the decision making processes of accessing and using health care for this population. In Nance-Floyd's (2015) unpublished work, unexpected findings regarding what illness means to NC NAs surfaced. These preliminary findings clarified the need for further examination of these issues among NAs in NC in order to understand how they defined illness and how they made decisions regarding their access of and utilization of health care.

In order to provide the best care practices in population health management, this qualitative study was essential. The purpose of this study was to understand the perception and experience of illness and how American Indians in southeastern NC describe their decision making process concerning access to and utilization of health care. Chapter 3 will detail the qualitative study that was conducted.

CHAPTER III

METHODOLOGY

Most American Indians (AI) in North Carolina (NC) live in rural areas. There is limited access to primary health care in these areas. Chronic illnesses have been a growing concern. The AIs in southeastern NC are greatly affected by disparities in health. There has been a dearth of research regarding these individuals who are part of state tribes and who do not have some of the resources provided to federally recognized American Indian groups. Understanding the beliefs that AIs have about illness and the decision making processes they use when choosing whether or not to access and use health care is essential for better health outcomes for this group. This study provided new knowledge to understand AIs' perception of illness and described the decision making processes they practice for accessing and using health care services.

This was a qualitative study using focused ethnography in southeastern NC. Self-identified AIs living in any southeastern county in NC ages 18 and above were eligible to participate. Gatekeepers were used to access the community, identify leaders, recruit participants, and coordinate recruiting dates and locations. Institutional Review Board (IRB) approval was obtained from the University of North Carolina at Greensboro (UNCG) and the University of North Carolina at Chapel Hill (UNC). Data collection included semi-structured interviews and focus groups and a researcher journal. Electronic data management and storage was provided by UNC through Pretty Good Privacy (PGP)

encryption software, Secure Network Attached Storage (SecNas), and through the Odum Institute Data Archive department. Hard copies of signed consents, participants' and gatekeepers' receipts, and confidentiality agreements were stored in the Primary Investigator (PI)'s home office temporally until they were moved to a locked office cabinet for storage at the University of North Carolina at Greensboro. Following confirmation of verbatim transcription, data was analyzed using inductive methods for open coding of themes. The identified codes were used in the qualitative computer software ATLAS.ti 7 to organize the codes. The findings were validated with the all of the gatekeepers and many of the participants before dissemination. A small incentive was given to the gatekeepers and participants for their efforts in assisting in this study.

The results of this study have the potential to open conversations with health providers and policy makers and provide foundational knowledge needed to develop disease prevention and health promotion programs that are specific for population health management. This chapter will discuss the methodology, a focused ethnography, and the operational definitions that were used to guide this study.

Purpose of Study

The purpose of this study was to understand the perceptions and experiences of illness among American Indians in southeastern NC and to describe their decision making processes when accessing and using health care services.

Research Questions

1. How do American Indians in southeastern NC describe illness/describe being ill?

2. What do American Indians in southeastern NC consider as important factors in their decision making process for accessing health care?
3. What do American Indians in southeastern NC consider as important factors in their decision making process for choosing to utilize health care services?

Methods

This study used a focused ethnography design to guide the study and the Social-Ecological Model (SEM) aided in the analysis of data. The SEM was discussed in detail in chapter one. The design of the SEM was illustrated (see Figure 1, page 24) as a set of nested structures beginning with the innermost layer to outmost layer. The Social-Ecological Model was used to situate the inductive analysis into context. Focus groups, semi-structured interviews, and a researcher journal were used for data collection. In the following section the study design, setting, sampling plan, data collection, procedures, and data storage and analysis will be explained.

Focused Ethnography

This focused ethnographic study permitted the study of the cultural phenomena (Munhall, 2012) related to health care access and utilization decision making for American Indians in the target group. Ethnography provided a truthful account of a particular culture using people's own words to grasp and defined the meaning behind social behaviors within the culture (Cruz & Higginbottom, 2013; Munhall, 2012). Cruz and Higginbottom (2013) explained that focused ethnography, also called microethnography, could be used to understand specific societal issues and relationships between people and their environment. It can also help to discover how people integrate

health beliefs and practices into their lives that affect nursing practice. Focused ethnography was an excellent choice for this study because it allowed for one researcher and a small sample size in a discrete community with episodic participation, in addition to being problem-focused and context-specific (Cruz & Higginbottom, 2013). This focused ethnography study was context-specific, understanding the perception of illness and the decision making processes related to access and utilization of health care, and focused on a discrete community with specific knowledge (AIs in southeastern NC).

Data collection methods for ethnography methodology includes field notes, case studies, participant observations, essays, storytelling, focus groups, experimental writing, and the inclusion of historical issues related to economics, education, or geography (Munhall, 2012). For this study, focus groups, semi-structured interviews, and a researcher journal were used. This qualitative design was effective in exposing assumptions that may have been otherwise obstructed allowing for more effective future intervention and health promotion research (Polit & Beck, 2012). Historically, AIs have not trusted the US government (Doyle, 2001) and may not have completed or returned a survey used in research. Therefore, their data may be missing. American Indians are storytellers by nature. Their history has been passed down through the generations narratively, making the qualitative methods of interviewing and focus groups excellent techniques to collect reliable data from this population.

Setting

Qualitative design requires an accessible population, one that conforms to the eligibility criteria, and is available to represent the target group (Braun & Clarke, 2013;

Munhall, 2012). According to the North Carolina Commission of Indian Affairs (2015), AIs in southeastern NC live in Bladen, Columbus, Cumberland, Harnett, Hoke, Robeson, Scotland and Sampson Counties. Four gatekeepers in various areas in southeastern NC were used in this study to help with recruitment and coordination of data collection. Gatekeepers were people who are members of the community who facilitate the researcher's access to the target population. The non-AI researcher had established friendships and trust with several tribal members over recent years. For this study, there was one lead gatekeeper and three southeastern area gatekeepers. The gatekeepers were trained and signed a confidentiality agreement (see Appendix D) prior to recruitment. Funding was available for the gatekeepers' services.

The setting for recruitment was considered purposeful because of the rich population of AIs in specific areas in southeastern NC and convenient because the gatekeepers chose locations that had easy access for the gatekeeper and the potential participants. The gatekeepers chose the specific recruitment locations within their county. Several gatekeepers from different areas were used so that different parts of southeast NC were targeted. Branching out into the southeastern community provided the opportunity to hear different experiences within southeastern NC. The recruitment venues were three (3) public buildings throughout the southeastern area of NC.

All locations had bathrooms, running water, electricity, and parking. After recruitment and consent, the participants chose the day of recruitment to conduct the focus groups and interviews.

Sampling

Qualitative research is focused on understanding meaning that are important to people and exposes individuals' multiple realities (Braun & Clarke, 2013; Houser, 2008; Munhall, 2012). It can be conducted with studies using smaller sample sizes than when using typical quantitative approaches (Braun & Clarke, 2013; Houser, 2008; Munhall, 2012; Polit & Beck, 2012). No attempt at generalizing to the target population was made. Smaller sizes may be used in quantitative studies with homogeneous populations and in qualitative studies (Braun & Clarke, 2013; Houser, 2008; Munhall, 2012).

The qualitative sample focuses on selecting people who will make good informants and is driven more by conceptual requirements than representativeness to the target population (Braun & Clarke, 2013; Munhall, 2012). The gatekeepers assisted in recruiting good informants. Inclusion criteria are self-identification of American Indians living in southeastern NC, English speaking, ages 18 and older who were willing to participate in a focus group or personal interview. This study used convenience and purposeful sampling methods.

Convenience sampling. Many nonprobability sampling methods provide opportunities to reach the AI population. Typically, convenience sampling, for example, may be thought of as problematic because it may not be *truly* representative (Polit & Beck, 2012). However, it is beneficial for attracting AIs for the non-AI researcher. Snowball sampling or networking sampling, a type of convenience method, was particularly beneficial when a gatekeeper was necessary and was used in this study. The trusted lead gatekeeper discussed potential participants with the three area gatekeepers. I

did not receive participants' name, address, or phone numbers from the participants or the gatekeepers.

Purposive sampling. In qualitative research, purposive sampling aims to find sample representatives of a broader group or set up the possibility of comparisons of interest (Braun & Clarke, 2013; Munhall, 2012; Polit & Beck, 2012). Purposive sampling assisted in comparing how one group, for example AIs living in one rural county compared to AIs living in another rural county, made decisions regarding access and use of health care differently than another group. Maximum variation samples, for example, are deliberate attempts for diversity within the sample whereas a homogeneous sample would deliberately narrow the focus (Braun & Clarke, 2013; Munhall, 2012). Having several gatekeepers in different counties helped to maximize the sample.

Purposive sampling was used to select specific stakeholders and experts from the population (Braun & Clarke, 2013; Houser, 2008; Munhall, 2012) such as the tribal employees and leaders. It was used for all recruitment efforts for focus groups and interviews (Braun & Clarke, 2013; Munhall, 2012). The lead gatekeeper assisted the PI by identifying and inviting tribal employees and leaders from several tribes to recruitment sessions. Then, at the time of the recruitment sessions, the gatekeeper introduced the potential participants to the PI. Four (4) focus groups were held (with a total of 15 participants) and three (3) participants agreed to personal interviews. Thus, the total sample size numbered 18 (n=18). Saturation of information was reached.

An incentive of \$10.00 cash was given to participants in the focus groups or the semi-structured personal interviews. Incentives were given upon completion of the data

collection session. Cash covered time and gas expenses for 60 minutes of interaction and was small enough so as not to be coercive. Appendix E illustrates incentive receipts. There was weekly communication with the gatekeepers during recruitment to address and anticipate the sample size, location, and chosen dates for recruitment.

Recruiting and Consenting

The gatekeeper invited potential participants and assist the PI in introduction and recruitment efforts using snowball, convenience, and purposive strategies. The gatekeepers used a telephone (see Appendix F) and face-to-face verbal script (see Appendix G) for recruiting purposes, developed by the PI. The PI validated gatekeepers' understanding of the telephone/verbal script through return demonstration by verbalizing the script to the PI prior to contacting potential participants. The gatekeeper either made a telephone call or made a personal visit to invite the potential participant to attend the recruitment gathering. Each gatekeeper assisted in deciding the best location for recruiting.

The telephone and the face-to-face recruitment scripts included, "A friend of mine, Betty Nance-Floyd... is studying how Americans Indian living in southeastern NC think about illness and how we make decisions on when and where we go for health care." Also included in the scripts,

If you agree to participate in her study, she will first ask you questions with a paper and pen survey. Then you will be asked to participate in a one-on-one interview or during a group meeting at a time and location of your choice. If you agree to an interview or group meeting, the interview and the group meeting should last about 60 minutes. Ten (10) dollars cash will be given to you if you participate in her study. You will also be invited to a follow up gathering once she has completed the study. She wants to confirm what she learned from you before she tells other people.

Finally, the gatekeeper gave the recruitment location, date and time and asked if he/she was interested in attending. The gatekeeper made a reminder call the day before the event to increase participation. On recruitment day, the gatekeepers introduced the PI. The PI told the potential participants that, at any time, if anyone wishes to leave, he/she may. It was said to all potential participants that neither the gatekeeper nor the PI would be upset or disappointed if anyone chose to leave. The PI met the potential participants, explained the study, answered all questions related to the study and then consent interested participants for the study. All potential participants stayed and became participants in the study. All participants chose recruitment and consent day as the data collection day. Bottled water provided by the PI was given to each participant and the gatekeeper.

The PI read the consent form aloud. The consent had been reviewed by two AI researchers for cultural sensitivity prior to IRB approvals. The consent form (see Appendix H) explained the following topics in detail a) General things you should know about research studies, b) What is the study about? c) Why are you asking me? d) Who is asked to participate? e) What will you ask me to do if I agree to be in the study? f) Is there any audio/video recording? g) What are the risks to me? h) Are there any benefits to

society as a result of me taking part in this research? i) Are there any benefits to me for taking part in this research? j) Will I get paid for being in the study? Will it cost me anything, k) How will you keep my information confidential? l) What if I want to leave the study? m) What about new information/changes in the study? and lastly, n) signature of voluntary consent from participant to include participants' printed name and signature.

After the consent form was read out loud to potential participants, time was allowed for questions and answers in a small space in the corner of the rooms for privacy. No participants had private questions. Yet, space was available. Pens were available for the participants to use for the short demographic survey. The gatekeepers assisted the participants in choosing to participate in either the personal interview *or* the focus group. A blank copy of the consent form was given to each participant to take home

Data Collection

Participant consent was obtained prior to any data collection as described above. The gatekeepers were not present during the interviews or the focus groups. Saturation was established with four (4) semi-structured focus groups and three (3) semi-structured personal interviews. Focus groups were 39, 35, and 43 minutes long and one (1) was one hour and 17 minutes long. The interview lengths were 22, 34, and 35 minutes long. Interviews and focus groups were recorded on two (2) digital hand-held recorders and transcribed verbatim. One recording was for back-up purposes only. The semi-structured focus group guide (see Appendix B) and semi-structured personal interview guide (see Appendix C) were reviewed by two AI researchers for cultural sensitivity before data

collection began. These guides were purposefully close in rhetoric to maintain continuity in the direction for both the focus group interviews and the semi-structured interviews.

Procedure for focus groups. After consent, the group met in an enclosed room for privacy in a public place that was chosen by the gatekeepers and participants. A picture of two of the settings and drawing of the third setting were included in the research journal. Once informed consent was obtained from each participant and consent was given to record the interview, the participant completed the PI designed demographic questionnaire (see Appendix A). These questions were related to socioeconomic status (SES) as described earlier in this chapter under the operational definitions. The PI provided pens. The completed demographic questionnaires were placed in a re-sealable envelope. Then, PI began by stating the following. “At any time during the interview, if any participant asks that the recording be stopped, it will be”. No participants requested at any time that the interview, focus group or recording be stopped. The participants sat at a table in an oblong circle type arrangement so that they faced each other to enhance open discussion. The PI stated the research title, *A qualitative study to understand the perception of illness and the decision making process for accessing and utilizing health care for American Indians in southeastern NC*. Next, the PI briefly explained the purpose of the study and the research questions. The PI read the following focus group script (see Appendix B).

Thank you for your time and for you sharing your personal experiences today. I am conducting a study to understand how you define illness and to understand how you make decisions on when, where, and how you access and use health care. You signed consent earlier and agreed to have the interview taped. Is that correct?

The PI waited for the answer “yes” before continuing.

I’m interested in understanding when you believe you are sick or ill and when you believe you are well. I’m interested in how you make a decision on when, where, and how you go see a health care provider. Basically, I want to understand how you make decisions on when and where to go to obtain health care and what, if any, differences there may be as to why some people seek a provider and others do not (transportation, safety, or other reasons). I would like for you to talk to in a conversational manner. It’s important that everyone has an opportunity to express him or herself freely. Let’s give everyone the chance to share their thoughts in the conversation by talking one at the time, please. Please make sure that your cell phone is off or on silent. I will be here mostly to listen and gently guide the conversation to keep us on track. I also want you to know that everything that is said is confidential and that your name will not be identified with anything that you may say or do. Again, I thank you for your time. Are there any questions? Let us begin.

The PI began with the first open ended question, “How do you feel about your current health?” as described earlier in this chapter in the operational sections. The complete semi-structured interview guide can be viewed in Appendix C. Upon completion of the focus group interview, the PI thanked the participants for their time and the \$10.00 incentives were given. The participants signed a receipt for the incentive cash. Receipts were kept in a separate file folder, in the cabinet with the signed consents. Participants were reminded that they would be invited to join a follow-up gathering at the end of the study to confirm the data. The gatekeeper notified each participant of the date and location for the end of study follow-up gathering (see Appendix I). Field notes taken during the interviews were added to the researcher journal. The digital recordings were transmitted within 8 hours via a secure line to the contracted transcription company, or private transcriptionist for verbatim transcription. Audio and transcription were validated

by the PI and the PI's research assistant (RA). Audio and transcription were randomly checked by a senior researcher committee member.

Procedure for interviews. After informed consent was obtained from the participant and consent was given to record the interview, the PI began by stating the following. "At any time during the interview, if you ask that the recording be stopped." No individual participants stopped the interview. During one individual interview, one participant stopped to answer his/her phone and quickly told the caller that he/she would call them back. The recording was not stopped; yet, the phone ring was recorded in the transcript. The participants completed the PI designed demographic questionnaire (see Appendix A). These questions were related to SES. A pen was provided by the PI. The completed demographic questionnaires were placed in a re-sealable envelope with the other demographic questionnaires.

The PI states the research title, *A qualitative study to understand the perception of illness and the decision making process for accessing and utilizing health care for American Indians in southeastern NC*. Next, the PI explained the purpose of the study and the research questions. The PI read the following semi-structured interview script (see Appendix C).

Thank you for your time and for you sharing your personal experiences today. I am conducting a study to understand how you define illness and to understand how you make decisions on when, where, and how you access and use health care. You signed consent earlier and agreed to have the interview taped. Is that correct?

The PI waited for the answer “yes” before continuing.

I’m interested in understanding when you believe you are sick or ill and when you believe you are well. I’m interested in how you make a decision on when, where, and how you go see a health care provider. Basically, I want to understand how you make decisions on when and where to go to obtain health care and what, if any, differences there may be as to why some people seek a provider and others do not (transportation, safety, or other reasons). I would like for you to talk to in a conversational manner. Please make sure that your cell phone is off or on silent. I also want you to know that everything that is said is confidential and that your name will not be identified with anything that you may say or do. Again, I thank you for your time. Are there any questions? Let us begin.

The PI began with the first open ended question, “How do you feel about your current health?” as described earlier in this chapter in the operational sections. The complete semi-structured interview guide can be viewed in Appendix C. Upon completion of the interview, the PI thanked each participant for his/her time; the \$10.00 incentive was given. The participant signed a receipt for the incentive cash.

Each participant was reminded that he/she would be invited to join a follow-up gathering at the end of the study to confirm data. The gatekeeper notified each participant of the date and location of the follow-up gathering (see Appendix I). Field notes taken during the interviews were added to the researcher journal. The digital recordings were transmitted within 8 hours via a secure line to the contracted transcription company or private transcription for verbatim transcription. The PI and the PI’s research assistant validated audio and transcription. A senior committee researcher randomly checked the audio and the transcripts.

Researcher journal. Immediately (within 4 hours) after each interaction with participants, researcher’s journal notes were documented. No names were written in the

journal. The participants did not keep notes and did not see the journal notes kept by the PI. These notes were transcribed onto the researcher's encrypted computer and transferred to the Odum Institute Data Achieves. All handwritten notes were destroyed. The journal became part of the researcher data. The researcher journal including copious field notes captured by the PI (see Appendix J) was gathered throughout the data collection period. Field notes were in narrative form using Dr. Marsiglio's (n.d.) *Conducting Qualitative In-Depth Interviews* as a guide. The journal had three parts: description, memos and field notes.

1. Description of the interaction to include participant's demographics, setting, time and main highlights of the interaction.
2. Memos that are divided into three (3) sections:
 - a. Theoretical memos summarized substantive and theoretical ideas that surfaced. What theory(ies) applies(y). What additional researcher readings needed to understand potential theories that have surfaced?
 - b. Methodological memos summarized what happened in the interaction that affected the way it was conducted, the quality of the data, comfort level, or exposure to relevant issue? How can/could that be changed for future interactions. What would I do differently?
 - c. Personal memos summarized how I felt during the interaction (nervous, relaxed, excited, bored, or other emotions). Did I feel inhibited to ask certain questions? How can/would I change this for future interactions?

3. Field notes were added for each interaction. These notes were non-verbal communication that was observed during the interaction and was later added to the transcript.

Data Management

Because of the history of mistrust among AIs with non-AIs (Cavanaugh, Taylor, Keim, Clutter, & Geraghty, 2008; Daher, 2012; Smyer & Clark, 2011) and non-AI researchers (National Congress of American Indians Research Center, 2012), the PI sought additional provisions for protecting data to promote comfort and participation among potential participants. Two hand-held digital recorders were used during data collection. Additionally, written data were collected. The digital recordings and the handwritten data were transferred to a secure data storage site. The first approach to data security was the encrypted password protected personal PI laptop. Second was the data archival department at the Odum Institute at UNC at Chapel Hill for de-identified data. Third was the sensitive audio data storage through the SecNas at UNC at Chapel Hill. Each of these data management resources were used. Individual and community member names were deleted from the transcript text and replaced with XXX. Provider names were changed to “PCP”. Brand names of medication were replaced with MED. Names of local community hospitals were changed to “alpha”, regional hospitals were changed to “beta” and large referral hospitals were changed to “Charlie”. Below describes the details of the data management.

Handheld digital recorder. Two hand-held digital recorders were used during interviews and focus groups. One digital hand-held recorder was used for a back-up

purpose only. Once the digital recording was confirmed and transferred to the PI's encrypted laptop computer, both digital hand-held recordings were deleted from memory (within 4 hours of data collection).

Digital recordings. A copy of each digital recording on the PI's encrypted laptop computer was transferred to the transcriptionist. A copy of each digital recording was transferred to Secure Network Attached Storage (SecNas) storage. Upon confirmation of the digital record in the SecNas storage, the digital recordings were deleted from memory from the PIs encrypted laptop. All interviews and focus groups were transcribed verbatim from the digital recordings. The transcriptionists and the company who were responsible for transcribing the recordings signed confidentiality agreements (see Appendix D and Appendix K). After transcribed by the transcriptionist, all recordings were deleted from the transcriptionist computer. After data confirmation with the gatekeepers and the participants, all digital recordings in the SecNas were deleted.

Written data. During data collection and analysis, written data were stored in the PI's home office in a locked cabinet. Long term storage of written data to include all consent forms, receipts, and confidentiality agreements were placed in separate folders in a locked cabinet at the University of North Carolina at Greensboro. Three years after dissemination, consent forms, receipts, and confidentiality agreements will be shredded by the PI. Demographic surveys completed by the participants were electronically converted to portable document format (PDF) for long term storage in the Odum Institute. The hard copies of the de-identified demographic data were shredded. Any

hand written notes during data collection were added to the digital transcripts or to the digital research journal. All hand written notes were shredded.

Personal laptop. Encrypted digital data were kept on an encrypted password protected and firewalled personal laptop computer of the PI. The laptop has Pretty Good Privacy © (PGP) encryption software installed. The encryption software was purchased by the University of North Carolina at Chapel Hill (UNC) School of Nursing (SON). The UNC SON information technology (IT) department performed the installation. All digital data were originally stored on this device until they were sent to the long-term digital data management storage location.

The Odum Institute. The Odum Institute (The Institute) was founded in 1924 and supports the teaching and research missions of UNC (UNC, The Odum Institute, 2015). The H. W. Odum Institute Data Archive is part of the UNC Odum Institute (The Institute). The Institute has the third largest computer-readable social science data archive in the United States. It archives national and international data. The Institute is a member of the Data Preservation Alliance for the Social Sciences (Data-Pass) which preserves and maintains secure access to datasets (UNC, The Odum Institute, 2015).

The Data-Pass follows all regulations that govern data to include the Health Insurance Portability and Accountability Act (HIPAA) of 1996, the Family Educational Rights and Privacy Act (FERPA), the Privacy Act of 1974, the Freedom of Information Act (FOAI), the code of Federal Regulations of Protection of Human Subjects, and the Gramm-Leach-Bliley Act (UNC, The Odum Institute, 2015). The Institute adheres to these laws by adopting practices including data are de-identifiable, statistical disclosure

controls, and usage restrictions (UNC, The Odum Institute, 2015). According to The Institutes' archiving specialist, the PI determines usage and user restrictions (Thu Mai Christian, personal communication, August 26, 2015). For example, the PI could be the only user with complete access to the dataset. The Institute has a system security with a private network, automated vulnerability scans and intrusion detectors, and encrypted logins (UNC, The Odum Institute, 2015). The Institute offered one of the most secure sites for data storage. Their partners in data security include the Institute for Quantitative Social Science (IQSS) at Harvard University and the Inter-university Consortium for Political and Social Research (ICPSR) at the University of Michigan, to name a few (UNC, The Odum Institute, 2015). An advantage to this partnership is that in the event the PI was no longer employed by UNC, these data can be securely accessed from a different university or location allowing the valuable work related to this population to continue.

The Odum Institute department of Data Archive located at UNC stored non-audio digital data. De-identifiable demographic data were converted to portable document format (PDF) and stored at The Institute. Digital transcripts of the interviews and focus groups were also transferred to this secure site. De-identifiable ATLAS.ti 7 data bundles and hermeneutic unit (HU) were stored at The Institute.

The Institute does not, however, encourage storage of audio data. Audio data is more difficult to de-identify and requires different storage abilities. The institute recommended Secure Network Attached Storage (SecNAS) through UNC.

Secure Network Attached Storage (SecNas). SecNas is a secure environment to store and manage sensitive data such as audio recordings. This service was provided by the University of North Carolina at Chapel Hill and adheres to all tier 1 researcher institutional policies and procedures for sensitive data (Karen Echoes and Richard Hill, personal communication, August 28, 2015). Karen Echoes is employed with the informational technology (IT) department with the UNC School of Nursing (SON). Richard Hill is employed with the UNC campus IT department and specializes in secure data systems such as the SecNas system. The SecNas environment has extensive audit logs that track any interaction with the file to include the unique Only Name You'll Ever Need (onyen) identifier, the computer IP address, and date and time of the interaction (UNC, Secure NAS, 2015). With the SecNas, the PI will manage access to this secure folder in the future. In the event of PI employment termination at UNC, the folder is destroyed by the UNC campus IT department (Karen Echoes & Richard Hill, personal communication, August 28, 2015). This stored audio was beneficial during data analysis. The PI accessed the audio for participant's reflections and tones that may not have been heard during the initial data collection and recorded in the researcher's journal. Access to these data recordings facilitated a more accurate analysis. Upon validation of the findings with the participants and gatekeepers, the recordings were deleted and erased from memory.

Data Analysis

To make sense of what was collected for this study, the data were analyzed using content thematic analysis. The researcher remained close to the data throughout the

process. This allowed for awareness when data saturation was reached. Transcripts from the four (4) focus groups (n=15) and the semi-structured individual interviews (n=3), along with the researcher's journal were used in data analysis.

Throughout the research process, Lincoln and Guba's 1985 criteria for rigor and trustworthiness were addressed (Polit & Beck, 2012). Credibility was established, first by conducting the data collection in a place chosen by the participants that encouraged the participants to share beliefs, and second through the confirmation of the analysis with the gatekeepers and participants. Dependability was established with participants' verbatim examples for each research question. An experienced researcher reviewed the transcripts, established codes and themes and feedback was given, thus establishing confirmability (Polit & Beck, 2012). The analysis process and final content analysis were also reviewed with two experienced researchers. Transferability or fit was established with the presence of meaningful quotes that can be applied by individual readers (Ryan, Coughlan, & Cronin, 2007). The following describes the process by which the data were analyzed.

Individual and focus group interviews were recorded and transcribed by either an experienced paid transcriptionist or the researcher's assistant, both of whom signed confidentiality agreements prior to the beginning of the transcription. Each transcript was checked against the audiotape for word for word accuracy by the researcher. The researcher made necessary corrections by adding text where inaudible text had been identified by a transcriptionist. There were only several areas within the seven transcripts where words within the recordings were unidentifiable to the researcher. Typed

transcriptions did not contain any identifiable information. Any participants identified in a transcript were XXX out.

The second comparative review of the recordings to the transcripts included the addition of the researcher's journal field notes. These field notes were added with parentheses and italics within the text. The third review of the recordings added the recording time in red within the transcript in five (5) minute intervals to facilitate quick access if needed. For example, [5:00] represented five (5) minutes into the recording. The researcher assistant (RA) also compared each recording to the appropriate transcript. Thus, each transcript was reviewed against the recording for a minimum of four times. The audio and transcripts were randomly validated by a senior committee researcher.

Next, the researcher prepared each transcript for analysis. As described in the researcher journal item number 1, description of the interaction to include participant's demographics, setting, time and main highlights of the interaction were added. The study title and three research questions were added to the top of each transcript. Page headers to identify the specific transcript and page numbers were also added to the transcripts.

The researcher's questions and comments were represented in the typewritten transcript by R: in Cosmic Sans MS 12 font. The participants' questions and comments were represented by P: in Times New Roman 12 font. The documents were renamed to represent the type of interview (focus group or individual), number of interview, date of data collection, and V or C. The letter V was added to represent "virgin" transcript that represented the transcripts without researcher's initial coding of data that was later uploaded into ATLAS.ti 7.

Once the transcript had been prepared for ATLAS.ti 7 upload, each transcript was reviewed again by the researcher and initial comments were added in the margin. This document was then named with the letter C. The letter C represented the transcript that included the researcher's initial comments in the margin that were later used in the coding. As suggested by Munhall (2012), the researcher gained intimate knowledge of each transcript by reading each a minimum of five times to identify codes, potential themes and noting personal reflections. After data immersion, the V transcripts were then uploaded into ATLAS.ti 7 for coding. Lopez-Dicastillo, Grande, and Callery (2010) suggest that computer software be used to facilitate coding of qualitative data (interviews and focus groups). Qualitative analysis computer software ATLAS.ti 7 was used to organize the data as well as to facilitate coding.

Open coding was inductively applied using the researcher's interpretation of the data. Codes assisted in recognizing themes. The codes were clustered into themes and subthemes. After the researcher's independent reasoning was applied to the data and the various codes, themes and subthemes determined, ATLAS.ti 7 query tool was used to illustrate the codes, themes and subthemes. As suggested by the Odum Institute (2015), ATLAS.ti 7 successfully provided query tools and graphical displays to illustrate the hierarchical and relational connections among the codes. These graphic illustrations are provided in the appendixes and are identified throughout chapter 4.

Chapter Summary

This focused ethnography study designed to understand the perception and experience of illness and how American Indians in southeastern NC describe their

decision making processes in regard to access and utilization of health care was described. The Social-Ecological Model was used to situate the inductive analysis into context, which will be described in chapter 5. Focus groups, semi-structured interviews, and a researcher journal were used for data collection. Content analysis consisted of inductively coding the data and sorting codes into themes. The ATLAS.ti 7 computer software program was used to organize the coding. The results from the data collection are in chapter 4 along with the codes and themes that were identified from the data during open coding. A discussion of the findings are in chapter 5 where the Social-Ecological Model (SEM) was used to situate the inductive analysis into context.

CHAPTER IV

RESULTS

Focused ethnography methodology was used to understand the perception and experience of illness and how American Indians (AI) in southeastern North Carolina (NC) described their decision making processes in regard to access and utilization of health care. Semi-structured focus groups and individual interviews were used to obtain answers to the research questions. This chapter will articulate the study findings to include the demographic profile of the participants and their responses to the researcher's questions that were used in the content analysis. Discussion of the content analysis and findings are in chapter five (5) where the Social-Ecological Model (SEM) was used to situate the inductive analysis into context.

Participants

Data describing the participants' demographics were compiled and are illustrated in Table 1.

Table 1

Participants Demographic Summary

Question	Answers	Total n =18
Gender	Females Males	n = 16 n = 2
Age ranges (<i>the individual's age</i>)	19- 45 years old 46- 64 years old 65 and older	n = 4 n = 4 n = 10
Work outside the home If yes,	Yes No Work full time Work part time (<i>One participant did not respond to this question</i>)	n = 6 n = 12 n = 2 n = 3
Insurance	Yes No	n = 15 n = 3
If “yes” to insurance, Type of insurance (s)	Private <i>only</i> Medicare <u>Additional to Medicare</u> Private insurance Medicaid Medicaid <i>only</i> Affordable Care Act (Obamacare)	n = 3 n = 10 n = 4 n = 3 n = 1 n = 1
Approximate miles to a health provider ranges (<i>the individual's response to mileage</i>)	0-9 miles 10-19 miles 20 and over miles	n = 6 n = 8 n = 4
Highest degree or level of school completed	Grades 1-11 Grade 12 with diploma or GED Some college (no degree) Associate's degree Bachelor's degree Master's degree and above	n = 4 n = 6 n = 2 n = 5 n = 1 n = 0

Participants (n=18) ranged in age from 23 to 91 years of age. Eight participants were below the age of 65. Two participants were male. Twelve participants reported that

they did not work outside the home. Of the six (6) who reported working outside the home, two (2) worked part-time, three (3) worked full-time and one (1) did not answer. Fourteen participants reported having insurance. Four (4) reported not having insurance. Of the fourteen (14) who reported having insurance, ten (10) reported having Medicare. Of those ten (10), five (5) reported having a private supplement and three (3) reported having Medicaid in addition to their Medicare. Of the participants who did not have Medicaid yet reported having insurance, three (3) participants reported having private insurance and one (1) reported having insurance available due to the Affordable Care Act (“Obamacare”).

Participants reported driving from one (1) to 45 miles one-way to see a health care provider. Five (5) participants reported driving less than ten (10) miles. Nine (9) participants reported driving ten (10) to 19 miles. In addition, four (4) participants reported driving 20 to 45 miles one-way to see a health care provider. The participants reported their highest level of education completed. Four (4) participants reported not having a high school diploma or GED. Of those four (4), completion of grades 7-11 were reported. Six (6) reported completion of a high school diploma or GED. Two (2) participants reported having some college without a degree. Five (5) participants reported having an associate’s degree and one (1) a bachelor’s degree.

Findings

The findings by research question follow. In each research question section, the questions posed to the participants related to that research question are provided, followed by the participants’ responses that were used in the content analysis. A

summary of the responses is given at the end of each research question. The discussion of the responses for each research questions is found in chapter 5.

Research question 1. How do American Indians in Southeastern NC describe illness/describe being ill? The question designed to gain understanding of how the participants described illness was: “How do you feel about your current health?” Follow up questions were related to the last time they felt really sick, an example of a time they believed they were ill, and to describe what they would like their health to be. Additionally, questions “What do you consider to be ‘good health’?” and “What do you consider to be ‘poor health’?” were asked to confirm the researcher’s understanding of participants’ responses when describing illness. The findings for research question 1 are represented under the headings representing the themes Illness (see Figure 2) and Good Health, followed by a Summary of Research Question One Findings.

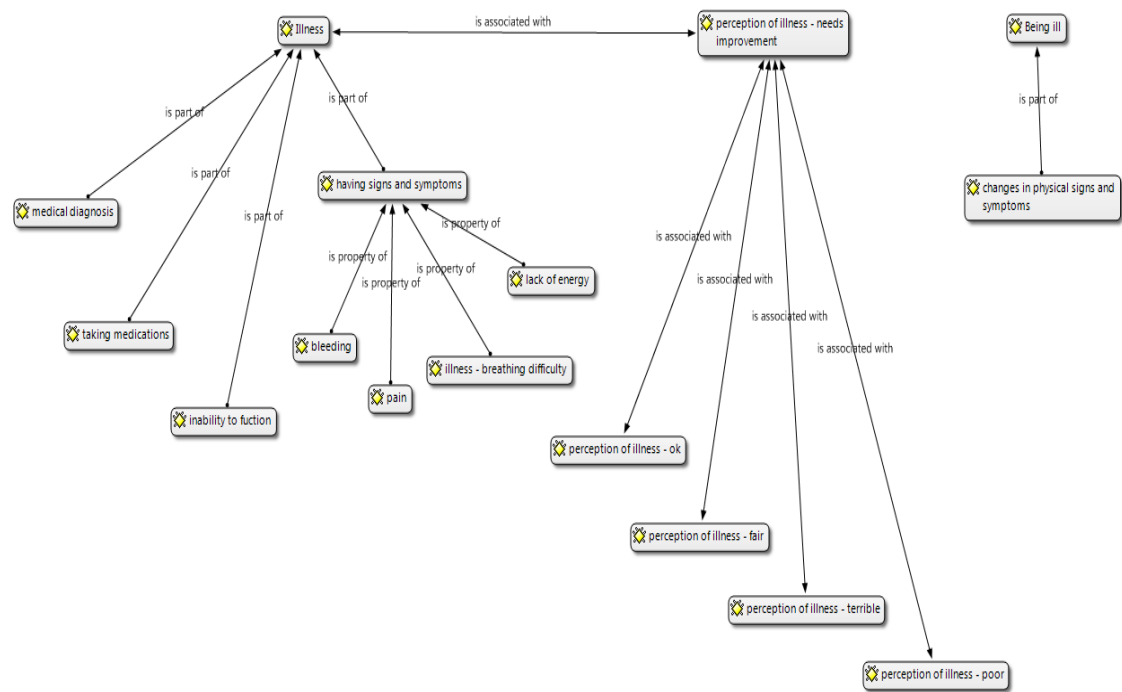


Figure 2. Perception of Illness and Being Ill

Illness

Illness was described as having many diagnoses, being “overweight”, needing a lot of medications, “lack of energy” and inability to function, and experiencing symptoms such as “difficulty breathing”, “having pain”, and “bleeding”. In the process of making sense of the data, the overarching themes that described illness were current or history of having medical diagnoses or surgery, the inability to function, and the presence of symptoms. The participants identified his/her current health on a range from “needs improvement”, “okay”, “fair”, “poor”, “terrible” to “good” health depending on their perception of current or history of having a medical diagnoses/surgery, inability to function, and/or the presence of symptoms. First, each participant was asked “How do you feel about your current health?” Below is how participants described those ways of

experiencing illness or being ill beginning with the first theme, medical diagnoses/surgeries.

Medical diagnoses/surgeries. These participants acknowledged the presence of current or past medical or surgery history or the need to take prescription medications when describing their health or being ill. One participant stated that his/her health “needs improvement” and explained,

Well he (*the provider*) said I was obese .. high blood pressure... And sometimes I get dizzy when I stand up too fast or working a lot... And I don't know if that is contributing to high blood pressure or maybe or artery blockage or something. I ain't no doctor so that is just my opinion about it.

Another described okay health as “I think I am doing okay, right now. I mean, I have some pain in my head. I been going to the doctor because I had the aneurysm.” Another participant described his/her “fair” condition as,

I've also had a hip replacement. I had a broken hip and I had that replaced and I had a open bypass, quadruple bypass. The things that I have had that I can name, blood clots, things like, that I've had. That is the reason that I say I'm in fair condition. I should say good condition cause I been blessed.

One participant described poor health as,

I would say I am in very poor health.... My list would go on and on. I have high blood pressure, diabetes, rheumatoid arthritis. I'm not really sure what they have diagnosed with -- I have problems with circulation blockages. I have a stent in my right artery in my heart. I have a stent in my left leg and a graftic [*graphic*] bypass from my right leg to my left because of a blockage. What else? I'm fighting kidney problems and probably some other things they just haven't found yet. I'm doing cardiac rehab three times a week for the heart attack.... I take probably 10-plus prescriptions a day, a shot once a week for arthritis, and along with doing my cardiac therapy.... But my health, at this point, is very poor.

Yet, another described poor health as,

I would say poor health, because it's not something that's getting better....I'm really expecting something else to pop up... I was diagnosed with diabetes. I started with 500 mg once a day, then I went to twice a day, now I'm at 1,000 twice a day. So the next option is going to be insulin.

Another stated,

...my health is terrible... I'm overweight as you can tell. (*grabs stomach*) I have high blood pressure. I'm on two different types blood pressure tablets. I'm on a fluid pill. I also take potassium tablets. And there's a couple other tablets I take. I can't remember the name of all of 'em.

The participants' perception of illness was related to the presence of, or the history of a medical diagnosis or surgery. Although, one may have considered himself/herself as in "good" health, when explaining the medical history he/she did not. The range of health (needs improvement, okay, fair, poor, terrible) was expressed by each individual differently. The second theme that was identified from the participants' description of illness was the inability to function. Below is how participants described those ways of experiencing illness or being ill.

Inability to function. Some participants described illness as when they experienced lack of energy or the inability to function. Inability to function also included the inability to attend or participate in family, social or work obligations. For example, one participant said, "I didn't have any energy. Mostly stayed in bed all day. And at times, my [energy] level dropped - I just dropped off to sleep." Another said, "I mean I can't do anything." One participant described, "When I couldn't do for myself. Like

when I got in the car accident I couldn't do anything for myself, so to me that's poor health." One participant explained his/her experience of illness as lack of energy.

I mean even using the machine and everything it was hard to breathe and I didn't have energy or breath to go hardly from one place to another. I mean it was awful; and, I couldn't eat; and, I was getting dehydrated because I couldn't drink because there was just nowhere for it to go. It was just like everything was, in the bronchial tubes everything was swollen up and there was just nowhere for it to go and that was miserable and I lost forty some pounds. I mean I just could not eat. I just couldn't force myself to eat and I was just, I almost wished I wasn't even living because that's how bad it was.

In the following example, the participant described illness as having a medical diagnosis, inability to function, and symptoms to support the progression of their illness. Although, the surgery was in the past and the participant no longer had symptoms, she/he expressed the inability to return to work as he/she explained being ill.

Well, my current health is not so good right now...I ended up having to go into the hospital...I stayed for 2 weeks... I had some polyps and things in my bowel line that was causing me to bleed and stuff...they reconstructed my bowel line everything. I couldn't do anything for myself because it was just so intense....when I came home I was very dependent on somebody because I couldn't get up and down very well and things like that, so I have been out of work since... Other than that, I think everything is okay.

The inability to function or participate in family or social activities was used to describe being ill whether or not the participant reported having a chronic illness or past medical history. The third theme that was discovered in the descriptions of illness by these American Indians was the presence of signs and symptoms of illnesses. Below is how participants described those ways of experiencing illness or being ill.

Presence of signs and symptoms. Some of the study participants described being ill as when experiencing symptoms of illness. One participant explained, “I had a temperature. I had a high temperature and I couldn’t breathe...you feel like you’re aching all over.” Whereas another participant explained, “And sometimes I get dizzy when I stand up too fast or working a lot.” One participant described, “...the bleeding got worse...” Another said, “When your body is consistently in pain and you go to doctors and you leave them the same way you came.”

One participant described how and when the symptoms appeared to explain his/her experience of illness, “That morning I had a pain that just hit me. It didn’t come on gradually. It just hit me.” Yet, another participant gave an analogy to describe the symptoms, “...something like a type of flu...”

Another participant described illness or being sick when he/she had symptoms of his/her medical diagnoses, “Well I have asthma (*participant speaking touched her chest*). So when my asthma flares up really bad. That’s when I’m sick. I start like getting tight in my chest and I wheeze and cough a lot.”

Participants described that they experienced being ill when they had symptoms of pain, bleeding, difficulty breathing, dizziness, and an elevated temperature. These experiences of being ill could exist with or without a medical diagnosis. When being asked to describe illness some participants shared the symptoms (lack of symptoms) they perceived were reflective of health.

To further understand what these participants considered illness or the description of being ill, each participant was asked, “What do you consider to be ‘good health?’” and

“What do you consider to be ‘poor health’?” Although describing good health was not a specific research question, understanding how the participants described good health compared to poor health assisted in the understanding of their perception of illness and served to validate the researcher’s understanding of the data.

Good Health

These participants described their perception of good health as opposite of their previously described perception of illness. Good health was described by these participants as not needing medications, the ability to function, and not having the symptoms of illness. Below are how participants compared good and poor health.

Not needing medication. Good health was described by one participant as, “not having to take medication.” Another stated, “Good health to me would be to be able to get up in the morning and come to work without having to mentally remind myself to go to my medicine cabinet and get a handful of medication.” Another participant said, “Not to have to take that medicine ... it would really be nice to get up and start my day and go throughout my day without having to worry about taking some type of medicine .”

Ability to function. The ability to function was considered then they described good health. One said, “Being active.” Another participant explained, “I feel like running, I feel like jumping, I feel like going shopping all day. I just feel good. I don’t have no pain or anything.” Where another participant described, “Being able to get out and do anything I need to do. My gardening - activities.”

Not having the symptoms of illness. Others described good health as the lack of symptoms. One participant said, “I wouldn’t have any pains.” Another agreed, “Without

pain” and others nodded in agreement. Yet, another explained good health to include lack of symptoms while being active.

Oh, I would just love to be able to do anything that I wanted to do. I would like to be able to go to a park and walk or go to a zoo and walk without my legs giving out on me and my shortness of breath and stuff.

One participant described his/her good health by contrasting a good day with a bad day in her life as,

The difference in a good day and a bad day -- a bad day is when I wake up, my head's hurting, or it's swimming, because I've done something wrong in my eating and my sugar's 200 and something, even with taking my medicines (*said “even with taking my medicines” real fast and with inference*). And good days are when my head's not swimming, I don't feel lightheaded or dizzy.

These participant responses related to their perceptions of good health validated previous explanations and descriptions of illness or being ill. They described good health as not needing medications, not having the symptoms of illness, and the ability to function. The following is a summary of the findings related to research question one.

Summary of Research Question One Findings

Study participants shared common thoughts about poor health and good health. Many participants described their perception of illness as having symptoms like difficulty breathing, lightheadedness, headaches, pain, and bleeding. The symptoms of pain and difficulty breathing were shared the most.

Some participants described illness by naming a particular chronic illness such as diabetes or a heart condition like hypertension with which he/she had been diagnosed. A

few expressed that obesity was a cause of illness and that obesity reflected illness.

Participants who had been diagnosed with a medical diagnosis considered themselves in poor health. Yet, if they were not experiencing symptoms of the disease and were able to remain active and function in social settings, they did not consider themselves as sick or being ill – only in poor health.

Then, participants said that once they had been diagnosed with an illness, they remained somewhere on the ‘needs improvement’ range of illness from okay, fair, poor to terrible health. The perception of being ill was dynamic and changed as the presentation of symptoms changed. Participants reported that if they were not on daily medications, did not have a medical diagnosis, and could be active and function in a normal capacity, they were in good health. Thus, illness, for this group of American Indians, is described as having one or more medical diagnoses or a history of surgery, having physical signs or symptoms of illness, and the need to take daily medications. Being ill is described as change in physical signs and/or symptoms, or lacking the energy or ability to function.

Furthermore, there is an important distinction between describing illness and describing being ill. Illness is described as having a medical diagnosis or history of illnesses or surgery. Being ill is described as the inability to function or having symptoms of illness. Illness is described as a noun. Whereas, being ill is described as a verb.

It is important to note that while making sense of the data, many barriers were found that could not be separated into access or use of health care services. Since the

intent of this research was to understand the decision making processes regarding accessing and utilizing health care for these AIs, learning why they did not access or use health care was equally important. It will be these barriers that must be overcome for a healthier AI population. Thus, barriers are identified later in this chapter as a separate theme, which emerged both in discussing access and utilization of health care. No real distinction could be made between the barriers to access and the barriers to utilization, thus they are combined. The following section will describe research question two and the findings after open coding and making sense of the data.

Research question 2. What do American Indians in southeastern NC consider as important factors in their decision making process for accessing health care? This question focused on when the AI participants reported that they accessed care, where they accessed care, who helped them decide to access care (see Figure 3), and why they did not access care.

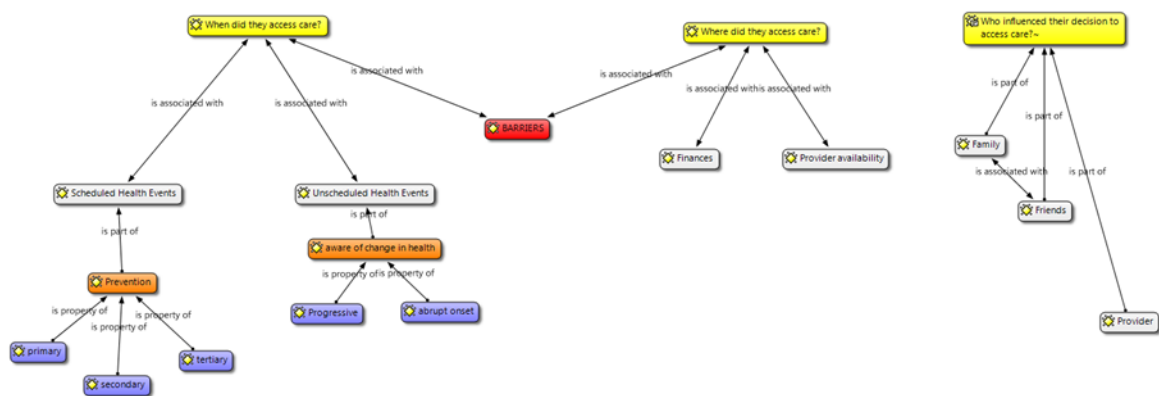


Figure 3. When and Where Care was Accessed, and Who Influenced the Decision

In the process of making sense of the data, themes and subthemes for each major category evolved. Below are how participants described their decision making process for accessing care beginning with category one, when care was accessed. First, the findings for research question two (2) are represented.

When Care was Accessed

This part of the research question was answered by inductive content analysis of the responses to the following questions. All participants were asked the same leading question. “How do you make the decision when to go see a health care provider?” Depending on the answer, follow up questions were altered slightly. For example, when the researcher needed clarity, follow up questions included, “Can you tell me the last time you did this?” or “Can you give me an example?”

The overarching themes that described *when* the participants accessed health care included ‘scheduled health care’ and ‘unscheduled health care’. More specifically, they decided to seek health care for scheduled, preventive services or for a progressive or abrupt change in health status (unscheduled). Below are how participants described scheduled events related to health care and their decision making process to access health care for these events.

Scheduled health care. Some participants described when they accessed health care, it was for ‘scheduled’ reasons. They included among these specific reasons such as annual physicals, follow-up appointments, vaccinations, blood work, or therapies. These scheduled reasons for accessing health care produced additional subthemes. These subthemes are what have historically been labeled as primary, secondary, and tertiary

prevention (Simons-Morton, McLeroy, & Wendel, 2012). Below are how the participants described when they accessed a health care provider because of a primary, secondary, and/or tertiary health needs or events.

Primary prevention. Several participants reported accessing health care when they needed an annual physical exam, vaccination, or preventative flu and pneumonia shot. One participant stated, "...some people really want to stay on top of their health and you know, make sure everything is ok..." One participant said, "Yeah. And, of course, about once a year, what do they call it, physical or whatever." One participant stated, "When he gave me my pneumonia shot I said, have you got a shot for bronchitis, because that's what I always end up with?" One participant described the relationship of primary prevention and social influence, "my mom and I go to the clinic over there to get our flu shots".

While a few participants did not receive vaccinations, "I don't do the pneumonia shot ... I don't do all of those things [*take vaccinations*]", and another participant agreed that he/she did not take the shots either, they did access care for other preventive measures such as annual physicals and check-up for medication refills. Most participants voiced that they partook in preventive care including a variety of vaccinations and annual check-ups.

Secondary prevention. Several participants stated that they accessed care when they had a follow-up appointment or for their annual physical exam regarding their current illness. Many spoke of seeing their provider every three (3) months. "I go every three months, and I have to go every (*pause*) once a month to get my blood drawn".

Several spoke about accessing a provider when they could not manage the condition on their own. “Yea, that’s me when my regular medicine’s not working or if I get a cold or something like that that I can’t shake.” Another one explained,

Well, usually, if I go to a doctor it’s not, thank God, it’s only been like my sinus issues. So, if MED stuff [is] not working, and it’s not clearing up, or nothing - it’s just too aggravating, I say, ok this is it. I’m going to the doctor. It’s usually like a sinus infection or something I can’t get rid of on my own.

Another participant added,

I get prompted to go to the doctor on a regular basis because my doctor really gets on me. He said I want to see you here every three months, every quarter or so, so we can keep a check on your blood work and see all what's going on. So that prompts me.

Without hesitation, participants described accessing health care when they felt professional care was needed or when a follow-up appointment was encouraged by a provider.

Tertiary prevention. Many participants explained when they accessed health care by describing ongoing chronic disease management with prescription refills, follow-up blood work, follow-up exams, and rehabilitation therapy such as cardiac rehabilitation. One participant said, “They tell me to use my albuterol machine to help clear it [*bronchial secretions*] up. And if that doesn’t help they give me prednisone to help it.” Another one added, “And, so I was going to physical therapy so I could move my legs and walk like I should”; and another commented, “I go to cardiac rehab

[*rehabilitation*]...” Yet, another participant accessed care mostly when a prescription is needed.

Usually I go simply to get a prescription for my blood pressure medicinefollowing what the doctor wants, I suppose, wanting to do bloodwork, lots of bloodwork, but I mainly go to get the prescription renewal, that's all. And if I didn't have to go there to get the prescription I wouldn't go.

Most participants explained they willingly accessed health care for primary, secondary, and tertiary health care needs that were scheduled for health prevention and health maintenance. During the process of open coding, another way participants described their decision making process regarding when they accessed health care was related to unscheduled health needs.

Unscheduled health care. Unscheduled health care became the second theme to emerge when understanding how these participants made decisions regarding *when* to access health care. Unscheduled reasons were primarily due to a change in health status. Two themes arose from these descriptions: Progressive events and abrupt events. Below is how participants described unscheduled reasons and their decision making process to access health care for these.

Progressive events. Progressive events are when physical symptoms of illness continue to worsen. As one participant described it, “...something like if you got a backache and it keep[s] bothering you, you need to have that checked out, cause it could be anything.” Another participant explained the progression of pain that led to an unscheduled emergency department visit.

Last time I went to a - the emergency room it was before a year ago. I think it was. I had a tooth and I couldn't kill it. I mean the pain. No medicine would kill the pain. So it was all I caught infected all. What do they call it? It's um [*an abscess*]

Abrupt events. Abrupt events are when physical symptoms of illness happen suddenly or without warning. For these study participants, these abrupt events included breathing problems, bleeding problems, excessive pain, or inability to function. One participant said, "If I'm hurting somewhere, like I have some problem with some pain here and here, yes ma'am, I get right out and get to the doctor that day." This participant described an abrupt aneurysm event,

That morning I had a pain that just hit me. It didn't come on gradually. It just hit me... I laid down on the couch and it won't getting any better. So I got up and walked down the hall... I said, 'Call my sister and the rescue squad I am not going to make it.' ... It was a pain like no pain I ever had... They called the rescue squad... I went to alpha area hospital. And then they called (helicopter) from beta area hospital; and they come and picked me up and carried me out there; and they operated on me out there.

These participants described that they accessed health care when they needed professional care outside what they could provide for themselves. They made appointments with providers based on their particular disease processes or for seasonal vaccinations (scheduled). They also accessed health care when unforeseen events such as a change in their health status occurred (unscheduled). It is clear that these participants access health care. Next, the major category regarding *where* the care was accessed is discussed.

Where Care was Accessed

To understand these participants' experiences as to where they accessed health care, each participant was asked, "Where do you go for health care?" Participants explained that they went to a "private doctor" (private medical clinic/primary care providers [PCP]), the health department (public health department), the clinic in alpha (a sliding scale Federally Qualified Health Center [FQHC]), "urgent care"(s), or emergency departments.

Next, the participants were asked, "How did you decide *where* to go?" The themes that arose from the data related to their decision making process regarding *where* they accessed health care and included finances and provider availability. Below are how participants described their decision making process on *where* to access health care.

Finances. Personal finances were a contributing factor to where to access health care for these participants. One person stated, "...when I couldn't afford to go to a doctor, I went to the health department." Another participant described that having a clinic that was accessible that he/she could afford assisted in the decision making process to access and use health care. This participant said, "... the reason I am going to this one [alpha clinic] is because I can go to this place and get my medicine cheaper, especially my MED. They say that MED is expensive." Another participant described how the FQHC assisted in his/her access to health services, "They [FQHC] base it on your income and a sliding scale - because, I don't have Obamacare. I'm just a student." One participant described how personal finances enabled his/her family to purchase an insurance policy that would allow access to particular hospitals.

...our health insurance for a family of four is \$1,700 a month. We pay a mortgage payment for Blue Cross/Blue Shield. We pay \$1,700 a month....Yes -- one thousand, seven hundred dollars a month for health insurance, and we don't have the best plan. We have a plan that Charlie 1 hospital and Charlie 2 hospital will take in case we ever have to go there. We could have went to a lower plan, but they (Charlie hospitals) would not have accepted it. If we would have went to, I think, the Select or something, or something different, but I was like no, we have too many issues -- family history issues -- not to be able to go to Charlie if we need to. So, yeah. My [spouse] pays ...So, basically, our health insurance is a mortgage payment.

This participant continued and described a time where having health insurance and money to pay the bill at the time of service assisted in the decision making process. This health facility offered an early payment savings plan.

October or November -- I had a heart cath [cauterization] and with my health insurance that we were paying \$1,500 a month, it went up to \$1,700, we had -- that morning my husband had to pay \$5,800 out of pocket. And we don't have the -- (pause), that was our part, the 20 percent that the insurance [*does not pay*], and if we had paid the \$5,000 then, or \$5,800, it was a savings versus putting it on payments [to the hospital] that would have been \$10,000 or so. So it was half of what we would have had to pay. Now I'm getting all these other [*bills*] - I've got one for \$3,000 and some laying on the counter now, all from this procedure.... And then they found nothing, so then I feel like an idiot for going through all that and spending that kind of money.

Although some spoke about choices for where to access health care as it related to financial means, others discussed financial means as a barrier to accessing care. This barrier will be discussed later in this chapter. Others explained that provider availability assisted in their decision making process on where to access health care. Provider availability will be discussed next.

Provider availability. Providers' availability was a factor that influenced these American Indian study participant's decision making processes to access health care.

Some participants described that when providers had office hours that were flexible and allowed for work and school schedules, they were more inclined to access those health care facilities. One participant said, “Yeah, cause I could get off early enough in the evening; where I went there at alpha clinic, they were open later in the evenings.” Another discussed the provider’s availability, “I think it’s [PCP availability] pretty ok. I’ll call and then she’ll [PCP] get me back there.”

The overarching themes related to the decision making process associated with *where* the study participants accessed health care included personal finances and provider availability. Barriers as described by the participants related to *when* and *where* to access health care will be discussed later in this chapter. Importantly, there was one theme that transcended research questions two and three - *barriers*. Participants reported that a variety of barriers prevented or delayed when and where they accessed and/or used health care. These barriers included personal choice, self-care remedies, dissatisfaction with the patient-provider relationship, dissatisfaction with the provider availability, lack of financial resources, lack of adequate insurance, and lack of transportation. A full description of barriers will be presented later in this chapter. Understanding these barriers assisted in clarifying why the decision not to access or use care was made by these participants. In the following section *who* influenced the decision making process related to *when* and *where* to access health care will be discussed.

Who Influenced the Decision

To better understand how American Indian participants in southeast North Carolina accessed health care, participants were asked, “*Who* else, if anyone, did you talk

to about it [accessing health care]?” The decision to access health care for preventive services was mostly a personal decision. Yet, two themes emerged from the data: family and neighbor influence, and provider influence.

Family and neighbor influence. Family and neighbor are combined into one theme as one participant explained, “Around here, your neighbors is about your family.” Family and neighbors were involved in the decision making process related to when and where to access health care for these American Indian participants. The participants described several occasions where they spoke to family and friends. As one participant explained,

See, the orthopedic that I went to wanted to do knee surgery right away. And I told my provider that I want a second opinion. So she got me an appointment in Charlie to a man, that, he had done surgery on a friend at church. And, he [friend at church] recommended him highly. So I went to him.

Another participant explained,

...And this [PCP] that I am going to now was recommended cause I needed to go see a doctor. And, I couldn't get one. And a friend of mine said 'well you can see my doctor'. She was his nurse and she was a friend of mine; and, she said 'well you can see mine tomorrow'.

And, another participant explained,

and my eye had swelled and they [daughters] said, 'Mama why your eye swelled.' And I said it's been running water today you know. And they said well it looks like bloods in 'em. So just. They had a fit [became anxious]. And they said, 'Get in the car. We carrying you to an urgent care'.

Clearly, family and friends were important social influences for these American Indians.

Provider influence. As explained earlier in the chapter, many participants reported accessing health care when their provider suggested preventive (primary, secondary, and/or tertiary care). The following is an example,

I get prompted to go to the doctor on a regular basis because my doctor really gets on me. He said I want to see you here every three months, every quarter or so, so we can keep a check on your blood work and see all what's going on. So that prompts me. I try to do that.

Although the persons who influenced the decision making process for each participant was individualized, the role of family and neighbors, and of providers was clearly present in the data. The following is a summary of the findings related to research question two.

Summary of Research Question Two Findings

These participants gave examples of when and where they accessed care as well as who influenced their decision making process to access health care. There were two themes related to when these participants accessed care: Scheduled and unscheduled care. These participants access health care for scheduled (primary, secondary, and tertiary) health care needs and unscheduled changes in health status. Health status changes were either from a progression of symptoms or an abrupt change in symptoms.

These participants access care from private providers, federal clinics, health departments, larger multiple-provider private clinics, urgent care and emergency departments. The themes that related to where they accessed care were finances and provider availability. Several needed the provider to be available and to be compatible with work and school schedules. The most influential people in their decision making

process in access care were family and neighbors. A few were influenced by their providers. Barriers that contribute to the decision making process not to access care are discussed later in the chapter.

The following section will describe research question three and the findings after open coding and making sense of the data.

Research question 3. What do American Indians in southeastern NC consider as important factors in their decision making process for choosing to utilize health care services? This question will be answered by the inductive analysis of the responses to the following question: “How do you feel about going to the clinic/hospital department?” and with a follow up question “What, if anything, do you wish could be different?” Trust for health care providers will be examined with a leading question “How do you feel about your health care provider?”, and a follow up question “Can you tell me about how you feel about trust and trusting in your provider?” “If someone asked you for advice on where to go for health care, what might you tell them?”

Two themes emerged from the participants’ responses to the questions related to utilization of health care services: self (intuition) and patient-provider relationship. As a reminder, there was one theme that transcended research questions two and three. This theme was the barriers that prevented or delayed access and/or use of health care. Recognizing these barriers is important because these barriers played a critical role in the decision making process for these American Indians in terms of their seeking health care. These barriers include personal choice, self-care remedies, dissatisfaction with the patient-provider relationship, dissatisfaction with the provider availability, lack of

financial resources, lack of adequate insurance, and lack of transportation. A description of barriers will be presented later in this chapter. First, the findings for research question three (3) are represented.

Self

Participants' decisions to use health care services were personal – even intuitive in nature. Participants described that they sought care when they *felt* like something was wrong, for example, “I knew [I had to go to the hospital]. I felt that I won’t going to make it.” Intuition was also used when influencing other family members, as one explained, “And that one time, I told momma, I said, something is not right. I said, I want to take daddy somewhere else.” One participant gave the following example to describe a time when he/she felt the need for health care based on symptoms being experienced. Yet, this participant also acknowledged that many AIs wait too late even when they know they should seek services.

There is times that I have felt bad and there is a couple of times when I was laying in the bed maybe a few weeks ago and a pain hit me here (touched her chest) and it brought me up off the pillow like this right here. And, I said I need to go to the doctor then. I believe that is what is wrong with the Native American people. We wait too late... But I have learned since I had the aneurysm, you need to go. There is a couple times I hadn’t but most of the times, I am at the doctor. Most of the time.

Waiting too late, many times, was a personal choice that delayed services.

Personal barriers related to why these participants waited are personal choice, self-care remedies (preventive or treatment), and dissatisfaction with their patient-provider

relationship. Personal barriers are discussed in greater detail later in this chapter as these personal barriers affect both access and use of health care for these participants.

Patient-provider Relationship

Participants described their interaction with their provider as part of the decision making process related to using health care services. Two subthemes were identified: satisfaction with the provider and dissatisfaction with the provider. Dissatisfaction with a provider is a barrier to accessing and utilizing services and will be described later in this chapter. First, satisfaction with the provider will be discussed.

Satisfaction with the provider. Participant satisfaction with the provider focused on the patient-provider relationship. Participants frequently expressed that a positive interaction with their provider was necessary for them to consistently seek and use the provider services. One participant said, “I have heard some say they had to go to different places to get a good doctor... Like Charlie 1 or Charlie 2, up that way. Yeah.” Subthemes within participant satisfaction with providers included provider communication and provider attitude. Below is how participants described satisfaction with providers.

Provider communication. These American Indian participants expressed satisfaction with providers when the provider communicated laboratory results, suggested to patients to make a follow-up appointment, or recommended additional services. During one focus group, two participants explained how provider communication follow-up resulted in satisfaction with the PCP. One explained,

They [*PCP office*] called the house. They usually pretty good. The doctor he [*grandfather*] sees now she's usually good about all that stuff, she'll check up on him and make sure he's got all this and that. He [*grandfather*] goes for regular check-ups. If for some reason he misses one, they [*PCP office*] call and try to figure out why, so,

A second participant added,

That's the way my husband's doctor is...and all his lab works they call it, well labs, or doctor's appointment. They call at least two days in advance with a reminder... Or he has an appointment and the doctor - something happened and he has to be out of town, they [*PCP office*] try to call a couple days in advance before that date and let him [*husband*] know so he [*husband*] can reschedule.

Several participants described experiences when they were satisfied with their PCP because the PCP followed-up or referred the participant for additional care when needed. As one explained, "...when I go if there's something going on that he's [*PCP*] not proud of [please with the outcome/result], he'll send you somewhere else." Another participant added, "She [*PCP*] says "well I'm not sure. I'm going to send you to the hospital' and they did an ultrasound on it ... so I was pleased with her that time."

Communication played a key role in patient-provider satisfaction for these participants. In addition to reviewing health reports, laboratory findings or exploring potential future needs, these participants explained that the providers' attitude *while* communicating was most important in their decision to use health care services.

Provider attitude. These American Indian participants reported satisfaction with their provider when the provider listened to them and made them feel that the PCP cared about them. One participant shared the importance of having a relationship with his/her provider, "... my doctor and I - we have a real good relationship.... Mm-hmm. I mean I

just love her. She's a very nice person and like I said, she's in no hurry." Another added, "So he's really good, for listening and ...". Another participant explained his/her satisfied feelings about his/her provider,

and now I go to one. I love her. She's really good. I'd tell anybody to go see her. Like she's real friendly. She talks to you like ya'll been friends for a long time. She explains everything that's going on. She tries to help you get discounts on stuff. If she - if you ain't got insurance when you come in there, she'll say ok well you can use this thing right here, call this number and they'll cut the price cause you don't want to pay the full price for this. So she's good.

Many participants said they would use the PCP services more when they had a relationship with the PCP. One said, "It's all in the way they act when they get in there [the exam room]." Having a good relationship with the PCP was important when deciding to use health care services. One participant said, "Makes it easier for you to just go." Another participant explained, "Well, I think the doctor should make you feel like that I can confide in you what's going on with me, and you'll listen and you're concerned." While another voiced, "Yeah. Because, to me, a doctor is somebody you're trusting your life with." One said, "But mine has been that way [nice] from day one, because I've been going to him for 20 years, I guess. And he's always treated me like his mother."

When their provider was not available, their relationship with the associate PCP was important to the participants. "And I didn't see my regular doctor, but I saw his associate, another doctor, and he treated me really nice, took time to ask me questions, and just treated me good." One added,

I had a doctor in alpha when he was living. Now, I liked him because he took time with you; and, if he couldn't figure out what was going on with you, he sent you somewhere else. Then when I'd come back he'd say, 'Well how did that person treat you?', 'How did that doctor treat you?', 'Were you treated the way you should've been?' And that I like, because he was concerned about where he sent me to, as well as the treatment that I got in his office. So I haven't really found nothing exactly like that [since he died].

If the participants had a good relationship with their provider, they would tell others to use that provider. During one focus group, two participants who shared the same PCP agreed they would recommend their PCP. Participant one explained, "This doctor took care of my husband, took care of my sister, and when they passed he said, well I'm going to take care of you as long as you live, so he's been very nice to me." And, "I can't say nothing bad about him." Then added, "So I would recommend him to anybody." Participant two agreed, "Yeah." In addition, "No, I can't – you can't say bad about him." Then, nodded his/her head firmly in agreement.

Having a personal relationship with the provider was a major theme that emerged when the study participants discussed their ability to access and use health care. Personal relationships with providers seemed to lead to participant satisfaction and to participants seeking and using health care services. Below is the summary of the findings for research question three.

Summary of Research Question Three Findings

Two themes, self (intuition) and patient-provider relationship, emerged in response to the questions related to the decision making process related to the utilization of health care services. Self was described as a feeling within. Patient-provider relationship was more diverse with two subthemes: Satisfaction and dissatisfaction.

Participants were satisfied when their providers communicated well, had positive attitudes, and were caring. These participants explained that when a provider listened to them and cared about them, they felt they could trust the provider more. These American Indian study participants were more inclined to use a provider with whom they had a positive relationship. Provider relationship was a vital part of their decision making process to use a particular provider or health care service. Dissatisfaction with providers was described as a barrier in the decision to access health care. Barriers will be discussed in the following section. These barriers emerged from the data related to both access and utilization of health care and should be considered related to each.

Barriers to Health Care

There was one overarching theme that transcended research questions two and three. This theme was with what the participants described as barriers to their ability to access and use health care. When participants decided not to access and/or not use health care services, at times, the meaning of access and use was blurred. Inductive content analysis through open coding to make sense of the data revealed an overlap in the data in the decision making process associated with *not* accessing and using health care. The following section represents the overlap related to the barriers that affected both access and use of health care services.

The intent of this study was to understand reasons that exist that would result in American Indian participants not to access and/or use health care. Each participant was asked, “What, if anything, gets in the way of your using the clinic/hospital/health department?”; “Why do you think that some people go to the clinic while others don’t

go?” “If they did not seek care, follow up questions were “Can you tell me more about why you chose not to?” “What, if anything, gets in the way of your using the clinic/hospital/health department?” with a follow up question “What about things like insurance, transportation, traveling/time, safety, or work hours?” Based on the data, barrier was divided into subthemes ‘intrinsic’ and ‘extrinsic’ (see Figure 4). Both result in a delay in treatment. Below are how participants described their barriers related to their decision making process in accessing and using health care.

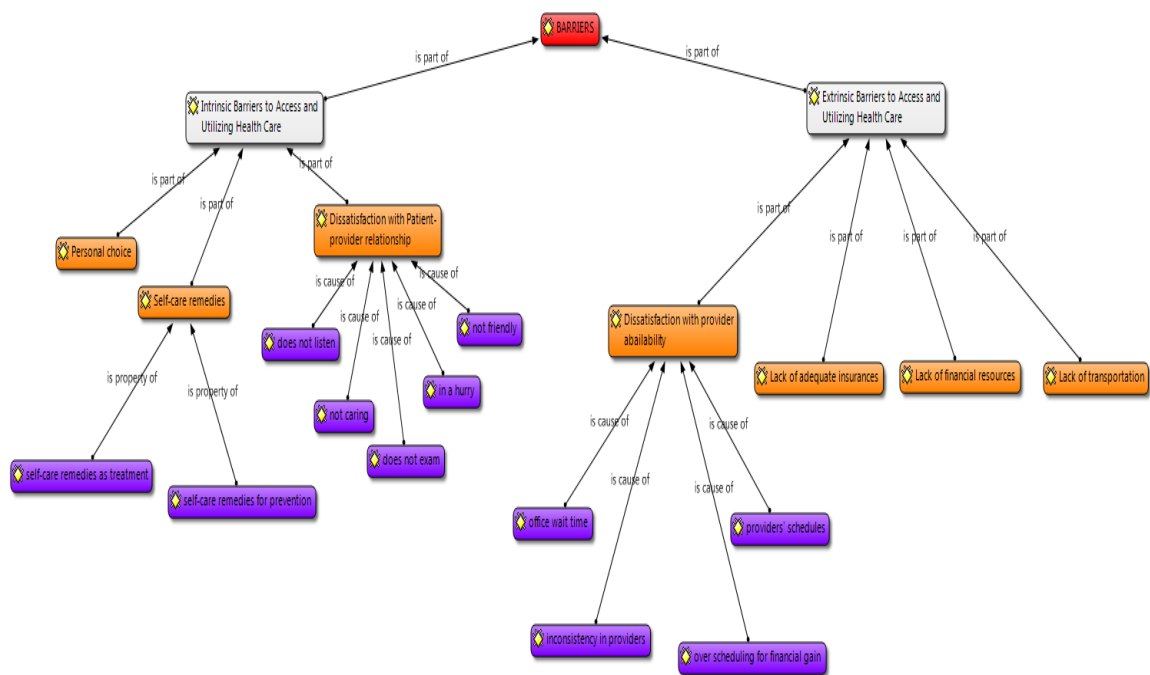


Figure 4. Barriers to Access and Utilization of Care

Intrinsic barriers to accessing and using health care. Intrinsic or self barriers were individual and personal. Intrinsic barrier further divided into subthemes to include:

personal choice, self-care remedies (preventive or treatment), and dissatisfaction with the patient-provider relationship.

Personal choice. Participants expressed their not seeking health care as a personal choice, “I don’t like doctors. I mean I just don’t.” Another person said, “...I don’t go [see a provider] that much unless it's absolutely necessary.”

Others explained that the personal choice that many AIs make might be due to fear. One participant said, “I think some people just be afraid that they're going to find out something bad.” Another one added, “They know they're sick, and some have insurance and some probably don’t have it, but they're afraid ...” And another one explained, “I think back to being afraid of what they are going to find out when they go...” While another person said, “I believe they are scared at what the doctor is going to tell them.”

Self-care remedies. Homeopathic remedies was one of the intrinsic barriers that emerged during several of the interviews related to not accessing and using health care. Self-care remedies are further subdivided into self-care for preventive reasons and self-care for treatment. Below are examples of self-care remedies used for prevention and for treatment of an existing problem.

Self-care remedies for prevention. These participants spoke about their appreciation for preventive health care. One participant said his/her family liked to use preventive approaches before accessing and using a provider. “Yes, we do. We try to avoid having to go (to see a provider).” Another participant added, “Some preventives.” Many of the participants discussed their spirituality, “My number one physician is Jesus;

I go to him first and then... He's brought me through what I've been through, so he's my real physician.”

Self-care remedies as treatment. Self-remedies for treatment are described by the participants as taking over-the-counter (OTC) medication for an existing health problem. Several described over-the-counter treatments by saying things such as, “Well, I wouldn’t go just for a headache. To me, you can go take something for a headache.” Another person explained, “This weekend when I had gout in my toe and I just didn’t get out of the house ... Then I have to take it [pain medication] to get shed [*relieve or get rid of*] of the gout... That’s the reason I got on flip flops today because I can’t put on my shoes.” One participant added that he/she used OTC before accessing or using a PCP, “No, cause I, well, I had in the past [used a PCP] and I know to use MED now. So I just go get MED and it hooks me up [makes it better].” Although, self-remedy was described as the first line of treatment by many, one participant gave an example where he/she regretted her decision to delay treatment,

Ahm, Yes, well see, now I see a dermatologist but before I didn’t cause I was trying to get rid of it myself. And it was working cause I was using a certain product for awhile and then it just ,I think the product eventually made it worse So I wish I would’ve went to her sooner instead of even using that other product. I can say that, which that product was known to be good... but it just didn’t work out for me. It made things worse. I wish I would’ve went to her sooner, that’s the only thing I can really think ...

Several participants spoke about specific self-care remedies. One said, “Yes, we do (use home remedies). My husband mixed me up one of his toddies, which is vodka, orange

juice, peppermint candy, and lighter, fat lighter splinters, - fat lightered, marinated.”

Another one added,

My grandmother used to make something with her peppermint and something else and whenever we got sick at home, it was in a special cabinet in the house. You went and took you a big swig of it and you went to bed wrapped up and you'd sweat it out, and the next morning you were good to go.

Although, considered a delay in treatment, these participants said they would seek other provided health care when their personal or self-remedy no longer worked. For example, several participants agreed that once their self-remedy did not work, they would go see a provider. One said and other nodded in agreement, he/she used a health care provider when “That I need help that I can’t do”. Another explained,

Something that I can’t handle. Now, if there is something that I can take or do to remedy the problem that I am having, then I don’t go. But if it’s something I can’t remedy, then it’s time I think for me to call somebody else that knows, hope they know, what they are doing.

Another said, “When you cannot take it anymore, you've tried everything to treat yourself or it's something that you just don't know what's going on, then you say, well, I better go see somebody.” These American Indian participants explained that they would access and use care if their self-care remedy no longer worked. Yet, they explained that their decision to access and use a particular provider for that care would depend on their (or their families) relationship with the provider.

Dissatisfaction with patient-provider relationship. Many of the participants gave examples related to dissatisfaction with providers as part of their decision making process

not to access and/or use health care. Aspects of dissatisfaction included having a provider that they felt “did not listen”, “did not touch me”, was “in a hurry”, and did not refer to a specialist when needed. One person said, “...He just ain’t got no patience. He’s not friendly at all. I mean just [*waves hands out and away*].”

Several explained their decision making process as to when they would change providers (related to dissatisfaction). One told this story,

When I go to my doctor and I sit there and I tell her exactly what's going on with me, and he even says -- I changed one doctor because I told him, I said, when I feel like you're not listening to me when I'm trying to tell you what's going on in my body, I don't need you anymore.

Another said,

Yes. If I go to one and he doesn't listen to me, doesn't take what I'm trying to express to him in words and he doesn't take it serious, and I feel like he's just in a hurry to just write something down and head on out -- no, I don't go back. I will find me somebody else. That's just the way it is. I'm not going to waste my time.

The following comment was made by a participant who explained a time when he/she changed his/her PCP.

My primary, I just switched. He had been my doctor because he was my mom and dad's doctor and he just got to the point that he didn't listen. I went in and he was just fumbled everything (*waved hands in the area, clapped hands and did padding motion*). Okay, we'll see you next time, and pat you on the back. Go by the lab. I was just like, no. So I just changed in November to a new one and she put me on this stuff and I'm still feeling her out.

Several participants voiced concerns that the PCPs “take on too many patients”, and do not “have the time” to spend with each patient. “Well, all these doctor offices are

about the same, they ain't got time.” Another person said, “I don’t know about nobody else's opinion. But when they take on too many people, I don’t think they give you the proper care that you should be getting.” Another participant added, “Cause a doctor probably see 25, 30 patients in a day, that's ridiculous. You can't give me the proper care that I need.”

One participant passionately added,

I mean, if a doctor takes on so many patients that they don’t have time for the patients, that don’t make sense to me. You can't (*pause*) we ain't cattles, we ain't hogs, we ain't an animal that you take in there... Well, I think the doctor should make you feel like - that I can confide in you - what's going on with me, and you'll listen and you're concerned. Even like when I talk to her about my bowels, she said, well when you come back I got a few little tricks that I'll tell you about. Well, I've been two times since then and I haven't heard about them yet ... You tell them the same thing when you go in, they still don’t hear you. That's what I'm saying, their mind is somewhere else.

Another participant responded, “She forgot; you got to remind her.” A follow-up question was “Does that change your level of trust in your provider?” Some individuals in the group responded. One began, “It did mine.” Another followed with, “It would.” And another person agreed, “Yeah”. A follow-up question to one participant who had previously expressed a satisfactory relationship with his/her provider was, “So, if you had a provider that you felt like you had this [*bad*] relationship - that she's describing, how would you feel?” The response was, “I'd probably say, well if you can't sit down and listen to me, you don’t need me to come over and you treat me and you take my money, and I'd probably go somewhere else.”

Another person told a story to explain her decision making process on accessing and using health care services when her trusted provider is not available.

If it [*an change in health status*] happened again, I would call [*my provider*] first to make sure that I need to go, I need an appointment to go and if my doctor was not there, I would not [*go*]. I would say well, ‘I will not see this other doctor.’ I will see – I think there’s three or four doctors in there. I would – as a matter of fact, I have refused to see her since then too. ... and so one time I got there and the girl [*office worker*], she says “Miss [XXX], I was going to call you and tell you that [*PCP*] is not here. She’s not going to be here today but today you can see [*another PCP*] without any waiting.” I said “no ma’am. I will not.” She [*the office worker*] said “okay, okay.

Another participant explained a time when he/she delayed treatment because of how he/she felt she had been treated by the PCP. Her condition eventually required surgery.

He didn’t even put his hands on me. He stood a distance like maybe I had something (*pushed hands away from her body*). And I was in there for my knee, so he sent me to do X-rays which was about a hundred dollars for a X-ray, and he goes, well I don’t see nothing but I’m not saying that there’s not nothing wrong (*shrugged shoulders*). So I went back home and a couple of months later, I had to find other sources to help me to get my knee checked. And, I ended up with surgery on it in 2013. (*pause*) So if you can’t [*touch me*], you got gloves you can put on, but that was my knee (*put hands to her heart*) and I was wearing shorts so, but it was like, I can’t touch you (*pushed hands away from her body*). (*pause*) I told myself, I definitely won’t be going back in there anytime he’s having to work (*wave hands off*). I mean, that’s your job, I’m sure you [*PCP*] put hands on your mannequins and stuff while you were going through doctoring school so, (*nodded head a quick yes*)

Several participants said if they did not feel that they could see their personal provider and felt they needed care, they would go to the hospital. One voiced, “If I get

real sick, I'm going to the hospital.” Another person agreed, “That's where I'm going.”

Another participant said, “If I don’t feel good, I go to the hospital.” One elaborated,

But if I felt as if I could not see my provider, I think I would try to seek out someone that I could trust first, but if I was really, really sick and couldn’t go to that provider, I'd just go to the hospital.

One participant described a provider that was available for patients in her area; yet, said she does not use this provider because of inability to have a relationship with the provider.

he [*the provider*] is from ... [*another country*] and does not respect women. Even if he had of given free care, I would not have seen him because he was so mean and rude ‘in his county’, he would say, ‘women aren’t allowed to talk’. He does not listen to women.

Having a personal relationship with the PCP is important for this group of American Indian participants. The relationship with the provider influenced their decision making process to seek care or not. A poor patient-provider relationship was a barrier when seeking health care. Next, the findings that support the second theme, extrinsic barriers, will be given.

Extrinsic barriers to accessing and using health care. Participants described experiences that they felt were outside their immediate control that contributed to their decision not to access or use health care. Extrinsic barriers include dissatisfaction with provider availability, lack of financial resources, lack of insurance, and lack of transportation. These barriers often resulted in a delay in treatment. Below are examples of how participants described these extrinsic barriers.

Dissatisfaction with provider availability. From the interview data related to dissatisfaction with provider availability emerged subthemes to include inconsistency in providers, providers' schedules, and office wait time, and over scheduling for financial gains that influenced the decision making process to access and use health care for many of the study participants. These issues resulted in delay of treatment for participants.

Inconsistency in providers. One participant in this study spoke freely regarding dissatisfaction when his/her appointment was changed from his/her "regular" provider to another provider. This participant explained,

...just like one time I had my bloodwork and stuff had been done, or I had had some tests done, well I'm expecting my doctor to be the one in there to tell me the results, and here I'm looking at somebody that don't know nothing about me. And, I just looked up and said, 'ma'am, I'm sorry, but you ain't the one I come to see', and I said 'and I'm not discussing anything with you because you going have to go in there and try to explain to him what I'm talking about cause I'm not discussing', he already knows that [*is how I feel*].

Another added,

The one that passed away, he had a PA and when he wasn't available I saw his PA, cause that was just who -- they were the only ones in the office, you know, these nurses and the PA, but I didn't have a problem with that. But when I go and you got two or three different ones, no, unh-uh, I'm not in agreement with that.

These American Indian participant shared experiences that having inconsistent providers was a barrier to access and use health services.

Providers' schedules. Several participants discussed their dissatisfaction with a provider regarding providers' schedules. One participant answered,

A lot of people. Yeah a lot of people have issues with that because they can't get off work; or, you know, they just can't make it. And if it a Monday through Friday clinic a lot of people can't go to the doctor because their employer won't let them off. Or, it's a hassle to get off. So, but you know, you do have a select few that have extended hours. I think most of the urgent cares do.... They do. The family practice closes at 5pm but the urgent care stays open until like 7 or 8pm. Participants described the hardship that limited provider availability created.

Office wait time. When asked about factors that create a feeling of dissatisfaction with the providers' schedules that may cause a decision to delay access or use to health care, many participants spoke of long wait times in the provider's office. The dreaded "back room" wait time was frequently voiced. One participant described the frustration of waiting for the PCP when the PCP had not arrived in the office.

... just like I went to an appointment yesterday. My appointment was at 9:40, I think it was. Anyway, when I went in and they done the test that I had to have done, they put me in a room. Well, right off the bat, I knew the doctor wasn't even in the building or anywhere because in the building, you can kind of hear when he's talking. (*another agreeing*) I'm like, he isn't even here. ...He finally shows up about 10:30. So you've got people that had appointments at eight o'clock had been sitting there. Now, they're [the other patients] out in the front and they don't know anything that's going on. But once I got to the back, you could tell that he wasn't even in the office. It would be very courteous if they would just walk to the room and say the doctor was on call last night, he had a surgery he had to do, he's going to be running late. If you want to stay -- if you can stay (*put pronunciation on "if"*), some people, like I'm taking time off from work (*another agreed*). So, I'll be like - I'll be back at a certain time from work. But if I'm sitting there three, four hours waiting for the doctor and him not even in the building, at least have the courtesy to come to the waiting room ... if you want to reschedule you can. They [*PCP offices*] don't. (*others agree*) I've sat in his office three hours waiting on an appointment and him probably not even in the building. But they never came and said that.

Another explained,

Yeah. Because if you give me an appointment for 1:00 then okay I understand emergencies come up but I should be back there by 1:30. And at least seeing the doctor no later than 2:00 at least, you know? Not sitting out in the lobby from 1:00 to 4:00 and then I see the doctor for 5 minutes at 4:05 and I'm gone. Okay, I sat here for 3 hours for 5 minutes and I still didn't tell you what was going on with me.

In one focus group participants discussed the frustration with the wait time and how the wait time influences decision making related to use of health care. One participant said, "When they give you a appointment and you have to go there and sit 2 or 3 hours after the appointment." (*other participants nod in agreement*) while another added, "And then if you late for your appointment, they act like it's your fault that a then when you get there on your appointment time you got to wait because their behind." Another person voiced, "Yeah the lobby is always full (*2 other participants nod in agreement*)."

One participant said, "And it supposed to been a couple hours for you and you think you not going to be seen that day and you might have to reschedule or" One agreed and added, "And a lot of times, if I have an appointment at 10 say 10 o'clock ...But, you sit there and you wait and you wait and you finally get back there [the back room]" Another snickered and said, "And then you sit there again (*3 other participants nod in agreement*). " One of those who nodded in agreement said, "And then you sit back there 45 minutes, cause I time it ... I open the door sometime to say 'have you forgot me?' I want to know if you forgot me because I sit back there so long (*2 other participants nod in agreement*). " One of those participants followed by saying, "And then they walking

down the hall and you think they are going to open your door and you still sitting and waiting there.” And yet another added, “I’ve been tempted to walk out.”

Another explained,

Well, all these doctor offices are about the same, they ain't got time. You go in there, and if you got an appointment -- with mine, I was in there last Wednesday cause I had an appointment, I had done blood work and they wanted me to come back. So I went back the next morning and here it is 11:00 and my appointment was at 10:15. I got right up there and cancelled that appointment and left.

These participants were passionate about sharing their feelings regarding the long and unnecessary wait time. They also expressed that the providers and providers’ office staff did not value their time as patients (consumers).

Over scheduling for financial gain. Many of the American Indian participants reported a belief that providers who are over scheduling patients do so for the providers’ financial gain. For example, one participant said “They want to keep you there because they want -- I’m going to say this and you [*the researcher*] can dot it out if you want to, it's a money thing.” Another person said, “My husband -- he's asking me, ‘When did I go to that doctor?’ I said you didn't. I said it was when you was in the hospital, they came by and waved at you, so you get a bill.” One participant explained her perception of how PCP makes money during a patient visit. “Then, when they write a prescription they'll get their extra money, okay (*looking at the other participants*)?” Another participant agreed saying,

And then I hear the lady say they get paid by the time they are back there [in the exam room]. He back there about 5 minutes talking to you and then he's gone. And you been back there 45 minutes. And he ain't back there with you about 5 minutes.

Another followed with, "It's all about the money." These American Indian participants shared beliefs that many PCPs were more provider focused than patient focused. Participants agreed that providers' schedules to include over booking patients for financial gain, prolonged wait time, and inconsistency of providers were barriers to receiving timely health care.

Lack of financial resources. Some participants explained that the lack of money either to pay the insurance copayment required or to make payments for the health care provided was a part of the decision making process that delayed treatment for health care. Several participants reported that not having insurance was a major barrier to access and use health care. One said, "Probably don't have no insurance." Another person added, "The financial thing, you got the copay you have to pay for. I don't care how much insurance you got there's always a copay." And another voiced, "Cause I don't have no insurance so it's more on me to pay." While another person explained, "... my son has none [*insurance*]. He's 24. He doesn't make enough money to afford the Affordable Care." As one participant described,

The last one I was scheduled for was to go back and see the results of my lab work and at that time he wanted to do a pap smear. They wanted to do a mammogram and a couple of other things that I knew that I didn't have the money to pay for. So. I didn't go back.

Another participant added to this conversation,

I have said I'm not gonna go cause I don't have it [*money*], but momma usually makes me go ahead and she just pays for it [service charges]. But I, I know people round here that's done that [not sought health care because of lack of money or insurance]. A lot of people actually won't go because they ain't got the money. Which I mean - why get over there if you can't pay for it.

Another participant followed by saying, "Why create another bill you won't pay when you didn't have the money to do it to start with? And I mean those [*test*] are expensive." Another described why some people in their area may delay treatment, "...can't afford it or they know if they go it is going to lead to something else [*test*] and they are going to have to have this test and that test and they can't afford to do it." One described how seeking health care contributed to current debt.

But, like my brother has to go to the hospital one time and he was still paying you see. He was still paying money on that cause he didn't have insurance for awhile. And that was just one visit about a stomach, some stomach virus that he had but he was hurting so bad that he had to go over there. That's a lot of bills to pay....He didn't have nothing to help him.

One explained how the employment has contributed to the financial barrier to access health care.

And a lot of our young people, they can't get the good jobs -- the welding jobs, which is primarily what's around here -- so they have to take a lesser-paying job. Well, with that lesser-paying job, they can't pay these insurances. They just cannot.

These participants explained how the lack of money to purchase the available insurance or to pay the required copay for the health care had contributed to a delay in

accessing and using health care. The following section is a description of how participants discussed how the lack of insurance or lack of having adequate insurance is a barrier for accessing and using health care.

Lack of adequate insurance. The participants without insurance or who had family members without insurance described the inability to qualify for adequate insurance as a reason to delay treatment. These participants explained how the lack of adequate insurance contributed to the decision making process not to access or use health care which led to the progression of an illness or health condition. One participant stated, “So the issue with us here, the majority of us in this community, I would say, is lack of insurance.” Delay in treatment for some health condition can progressively lead to an abrupt condition requiring immediate health care. One participant described the details of her delay in treatment because of lack of insurance.

Well, I had been having other issues polyps other places. Like I had those cysts that you have in your breasts. I have had them in both of mine. And I have had 3, 4 surgeries, 2 on each side. Other than that, you know, I thought well everything else is okay. And then I started having these issues with the bleeding and stuff like that. Well, the bleeding got worse when I sat down on the commode. It was like a big brook [but] just a clot fell out. Well, my momma thought well, ‘your having a miscarriage’ or something. That is just how bad it was. And, so I was like no - there can’t be. Any way, you know, none of that, so, whenever we got to the hospital he (*the provider*) just said I had a lot of internal bleeding and that all of it just came out at once. So, and before then, I did not have health insurance. That was a big issue; because, I just I couldn’t afford health insurance. And with my provider, still, you know, with my employer, still I couldn’t afford it. So, cause we have to pay for our health insurance. So it was just a mess. So then they stopped offering ... they cut our health insurance out because everybody was getting it through the Obamacare. So once we were able to get it through Obamacare then that is when I received health insurance. ... I did not see a doctor unless I just definitely had to go to a doctor. And then, I would try to go to one that I knew, that, you know wasn’t going to charge me out the roof to see them or whatever.

This participant explained that her symptoms began before she had insurance.

She continued,

Yes ma'am, I was having it a little bit [*bleeding*] it was not as much. And it gradually got worst and worst. Cause I thought well, you know, maybe it is something minor, maybe I strained; or, you know, maybe I am just -I had, you know, a tendency to become constipated often. And so, I thought maybe I just strained or it was something like that. But it kept getting worse and worse. So, that one day - I didn't have a choice. That was in September. So I stayed in the hospital those 2 weeks and was out of work from September to present [*January*].

One participant who had insurance under the Affordable Care Act said,

I don't have insurance, that's why I asked could we talk about Obamacare....I did have it to start out with. I didn't have to pay but like 24 dollars and something a month. Well I could do that. And see he [*Obama*] says he's [*Obama*] going to make it affordable for everybody. Well my job ended. It was time to renew [*insurance – Obamacare*]. So when I called'em, they told me I didn't qualify for any discounts cause I did not work. And my income was not high enough. So, I could pay 500 and some dollars a month. And I told, I said my husband's on disability. We living off of his check which is like eleven something a month. I said, even if off of his, I can't afford no 500 and something. 'I'm sorry you're upset but there's nothing I can do' (*the person the phone told her*). So that's where I'm at now.

Later, this participant described a delay in treatment related to lack of insurance.

I don't go [*to a health care provider*]. I just try to work through it (*shrugs shoulders*). I know I should; but, I can't see creating more bills that you're gonna pay forever and never be able to pay them off. Which I'm the one hurting myself, but that's why I said his [*President Obama*] affordable insurance, just isn't working.

One participant explained his/her feelings about the available insurance in the community.

But, I say the number one reason a lot of our people do not go is no insurance and having a good insurance -- any insurance ain't a good insurance. It's just not. It may get you in the door, but what you've got to pay when you leave out that door, you might as well not have it. So it's affordable insurance that we do not have. Forget the Obama thing. It's not affordable.

Another participant described a family member's inadequate insurance and it relayed to a delay in treatment.

And if they do have [*insurance*], like one of my daughters, her husband's company offers insurance, but when she went to use the plan, it was ridiculous what they paid on her hospital bill. I said, 'you need to go to the doctor.' She said, 'I can't go. The insurance don't pay.' So therefore she doesn't go to the doctor because her insurance isn't any good.

Another person explained a time that a member of the community delayed treatment due to lack of adequate insurance. In this example, the decision to delay treatment resulted in death.

Well this one individual, the doctor had told him that he needed to go [*for a test*] he was having issues; and, he needed to go have an MRI done. Well he couldn't afford the MRI because it was like, I think, out of his pocket he was going to have to pay 700 dollars or something. And, he couldn't afford it. Well three weeks - it might have been maybe a month down the road - he was at work and just fell. When he fell he had had a massive heart attack and he, the doctor, said some type of blood clots or something. That is what they [*providers*] had saw and they [*providers*] had wanted him to have an MRI done. And, with his insurance they told him 700 dollars and that they would have to get it approved. Well he couldn't afford the 700 dollars and because he is a working father and he couldn't afford it and he fell dead at work.

A follow-up question to confirm the outcome of the community member was, "And died?" The response was. "He died." The American Indian study participants gave many examples when the lack of adequate insurance created a barrier to timely health

care. Several described when the delay in treatment because of inadequate insurance caused financial burdens, prolonged illnesses, and at least one unnecessary death in their community. The lack of adequate insurance was a factor when deciding to access and use health care for these participants.

Lack of transportation. Although for some of these participants, transportation was not a barrier for accessing or using health care, other participants stated the people in their area did not have transportation. As one said, “Might not have transportation to go [to a provider].” Some had a car but did not have the money to buy the gas needed. Others had a car, but were not physically capable of driving. There are no public buses or railways in the rural areas where these participants live. Some participants described that the local public free bus for health care appointments was for only Medicaid participants. For those who were eligible, the Medicaid bus had a limited schedule. In one rural area where many of the participants reported traveling 10 to 40 miles for health services, the participants strongly agreed with each other that appointments for services had been missed because of lack of transportation. One stated,

They [*neighbors*] might call and say do you know anyone that could drive me to the doctor? I have an appointment, I don't have transportation.. And some of them actually have vehicles, they're just at the point that they can't drive right now, and they'll ask. [*for transportation*] I had one lady call and she said I have a car, I just don't have nobody to drive me on the day of my appointment. We try to find them drivers.... they do have a transportation bus that comes. But it comes so early that if you get on that bus, your appointment might be at one o'clock but you've got to be on the bus because somebody has a nine o'clock appointment, and you might not get home until after five because you're on this transportation bus.

When asked if they knew how often this bus provided access to the health care, one replied, "...they drive it [*Medicaid transportation bus*] every day, they probably do, but not in our area. It's all for the county."

One participant explained,

It [*local transportation*] is through Medicaid (*stated with infancies on caid*) you have to have Medicaid (*infancies on caid*), I think. And then you still even if you get Medicaid (*infancies on caid*) you still have to pay, I think it is 3 dollars or something to ride the bus to go to a doctor's appointment. I don't know if that's one way or that's for the whole trip, I'm not sure.

As a follow-up question to better understand, "I was wondering if it might be difficult to get an appointment [*on the bus*]?" The participant followed with,

It is hard to get I know that for a fact. Because where I work, we have several that ride that bus and you got to get it on a certain day at a certain time. You can't have it before this time and after that time. It's very hard to get.

Another participant explained,

I know people who don't [*have access to transportation*] around here but that is a situation for some people. I mean, I haven't ever had that issue; but, I do know people personally that have had that issue [*no transportation*] ... Either they get somebody to come get'em. If they can't get that - then that's - I mean that, there's no way to get there... I know a couple people. I know people who've got on Facebook and say 'can somebody take me to such and such'.

Although some participants did not consider transportation a barrier to accessing health care, other participants who had to travel a longer distance to access health care found the lack of transportation to be a barrier to health care. For many American Indians in rural southeastern NC, transportation was a barrier.

Summary of the barriers to accessing and using health care. These participants described many of the same barriers when deciding not to access or use health care. The themes for why participants did not access and use health care were intrinsic and extrinsic in nature. Intrinsic barriers included subthemes such as personal choices, self-care remedies (preventive and treatments), and dissatisfaction with the patient-provider relationship. Dissatisfaction with the provider was primarily related to the lack of a personal relationship with the provider.

Extrinsic barriers were barriers that the participants felt they could not control. Extrinsic barriers were dissatisfaction with provider availability, lack of financial resources, lack of adequate insurance, and lack of transportation. Of these extrinsic barriers, the one most often reported was the lack of adequate insurance. Not having insurance or the money to buy affordable health insurance created a delay in treatment for many of these participants.

Chapter Summary

This chapter conveyed the findings that emerged in the content analysis of this focused ethnography study that was designed to understand the perception and experience of illness and how American Indians in southeastern North Carolina (NC) described their decision making processes in regard to access and utilization of health care. Eighteen American Indians in rural southeastern NC participated in semi-structured focus groups and individual interviews. The findings to support the themes that emerged from the content analysis for each of the research questions were provided. Having an illness and being ill were described differently by these participants. Illness was

described as a noun; most typically by using a medical diagnosis to support the explanation. Being ill was described as a verb including symptoms of illness or inability to move or function.

The decision making process of accessing health care was organized according to when and where these participants accessed care as well as who influenced their decision making process to access health care. Each category had distinct themes. The themes that were exposed related to the decision making processes for accessing health care included a) when - scheduled and unscheduled health events, b) where - finances and provider availability, and c) who influenced - family and neighbors, and providers. The decision making process for utilization of health care revealed two major themes: self and patient-provider relationship. Subthemes were identified where appropriate. Barriers, intrinsic and extrinsic, transcended the decision making process *not* to access and utilize care by most of these participants. Themes and subthemes emerged from the data during the content analysis. In the following chapter, discussion of the findings including examining the findings in the context of current literature will be provided. The Social-Ecological Model was used to situate the findings and analysis into context.

CHAPTER V

DISCUSSION

American Indians (AI) in southeastern North Carolina (NC) live in rural areas with limited access to primary health care. These AIs are greatly affected by inequities in health, particularly chronic illnesses such as heart diseases, cancer, and diabetes. These chronic diseases cause long term consequences. It is essential to understand AIs perception of illness and their decision making processes they use when choosing whether or not to access and use health care. It is generally accepted that early detection of illnesses and receiving primary health care has the potential to significantly reduce negative health outcomes. There are many ways by which health and illness are influenced. If AIs are not seeking timely health care, it is important to understand why they are not. For better understanding, it is important to speak with American Indians so that their voices can be heard. By gaining an understanding of critical aspects of health care decision making for American Indians in rural southeastern NC, it will be possible to design more effective strategies that could promote access and use of primary health care for this population in order to begin to eliminate the health disparities they face.

In chapter 4 the participants' experiences understood through analysis of semi-structured focus groups and individual interviews were reported. This chapter will provide a further description of the data, examine it in the context of current literature, and situate the findings within the Social-Ecological Model. Additionally, this chapter

will provide a graphic depiction of how AIs make the decision to seek care for unscheduled health care that was designed based on the participants' report. Recommendations for future research, practice, policy advocacy and education will be offered.

Research Questions and Social-Ecological Model

The Social-Ecological Model (SEM) was used to situate the inductive analysis into context. The SEM (see Figure 1, page 24) is a set of nested, expanding layers that place the individual at the center and further expands to include larger systems. As described in chapter 1, the SEM constructs and variables within the Social-Ecological Model were used.

As the model predicted, the participants' decisions were made resulting from the influences of the various layers of the SEM. There was interaction between the SEM layers and each layer built upon the other from the inside layer toward the outside layers (from an individual, to the social environment, to the physical environment, and finally to policy). The individual was always the core and focus of this model. The following will describe how the data from each research question corresponded to the SEM model.

Research Question 1

(How do American Indians in Southeastern NC describe illness/describe being ill)? Three of the SEM layers were identified in question number 1. Below is how microsystem/individual, mesosystem/social domain, and macrosystem/policy were described by the participants.

Microsystem/individual. Illness and being ill were personal experiences. These participants had knowledge of particular illnesses and gave specific examples of their medical diagnoses and symptoms that they felt supported their definition of being ill. They acknowledged that two people with the same symptoms may have different perceptions of being ill. For example, individuals identified times where one person considered himself/herself as being ill that was not necessarily considered ‘ill’ by another person. Although the perception of illness or being ill was mostly reported as an individual experience (microsystem/individual), there was an overlap of this level of the model in the individual and the mesosystem/social domains.

Mesosystem/social. There was a link between the microsystem/individual and the mesosystem/social domain for question 1. For example, if the primary care provider (mesosystem/social domain) gave the participant a diagnosis, the participant (microsystem/individual domain) believed he/she was ill or had an illness. In addition, if a family member (mesosystem/social domain) knew of a diagnosed medical condition for an individual (microsystem/individual domain) or vice versa, the family member or the individual believed the other person to be ill and encouraged treatment. Or, if the family member witnessed signs and/or symptoms of illness, the person experiencing these manifestations was considered to be experiencing an illness (to be ill).

Macrosystem/policy. The macrosystem/policy level of the SEM influenced these AI participants’ perception of illness, or at least, the perception of the degree of illness individuals and communities experienced. For example, several participants commented on their county health rankings as “100” (the worst rating in the state). Another person

spoke about how the insurance prices were higher in his/her county because of the high rate of illness. Their perception of illness was influenced by county and state health rankings.

Research Question 2

(What do American Indians in southeastern NC consider as important factors in their decision making process for accessing health care?) The microsystem/individual, mesosystem/social environment, exosystem/physical environment, and macrosystem /policy domains were reflected in the decision making process related to when care was accessed, where care was accessed, and who influenced the decision to access care.

Below is a description of how the SEM levels are reflected in the text.

Microsystem/individual. The participants had knowledge about where and when to access health care. Where Paskett and colleagues (2004) and Wells, Caplan, Strauss, Bell, and George, (2010) found that people in Robeson County, NC lacked knowledge about where to receive health screenings and health clinic location preferences as barriers to the access to health care, the participants in this study spoke about the available health service opportunities (private providers, a sliding scale Federally Qualified Health Center (FQHC), health departments, urgent care settings, and emergency departments). The participants in this study reported that they accessed health care for scheduled and unscheduled (unplanned) health events. Persons were knowledgeable about scheduled events such as vaccinations, follow-up appointments, and rehabilitation appointments. Although these participants were not identified with a specific tribe, these participants engaged in preventive and screening measures if they had health insurance or money to

pay for services regardless of age or educational status. This is different from what Farmer, Bell, and Stark (2005) reported. Those authors found that cancer screening correlates for Lumbee Tribe participants were better for persons with higher education, over the age of 40, and among those who had healthy lifestyles. In contrast, this study identified that having health insurance influenced the decision making to access preventive care.

Unscheduled events were health care visits made due to changes in health status. These AI participants described a relationship between personal finances and community poverty related to poor community economic growth as a barrier to accessing care. These financial barriers will be described later in this section. Much of the decision making surrounding accessing health care for scheduled events was personal. Yet, other domains from the SEM influenced these decisions.

Mesosystem/social. As expected, the AI culture focused on comradery and community. Family and neighbors influenced these AI study participants' decisions to access health care the most. This research added to current knowledge related to how these AIs in rural southeastern NC access health care. Smyer and Stevig (2007) noted that AIs from federally recognized tribes are family centered and that family interaction deeply influences decisions and life choices; and, AIs depend on their family for supportive care and the recommendation to seek out health care (Smyer & Clark, 2011). The same was true for this study. Provider's influence on a patient's health typically followed an interaction between patient and his or her family or neighbor.

According to the United States Department of Labor, the Bureau of Labor Statistic (2016), North Carolina's unemployment rate for December 2015 was 5.3% (not seasonally adjusted) and 5.65% (seasonally adjusted). Yet, in the counties where many AIs in southeastern NC live, unemployment rates were much higher. For example, in the 2015 State of the County's Health (SOTCH) report for Columbus County, the unemployment rate for the county was reported at 12.6%. Further, it was reported that 21% of the residents are uninsured (Columbus County Health Department, 2015). For Bladen County, the latest available SOTCH report documented unemployment as 8.8% and the percentage of persons living below the poverty line was 24.4% (Bladen County Health Department, 2014). Further, in Scotland County, the unemployment rate was reported as 10.2% and the poverty rate as 30.6% (Scotland County Health Department, 2014). In Robeson County, unemployment was reported as 13.3% and persons living below the poverty level was 30.6% (Robeson County Health Department, 2013).

Unemployment accounts for the lower socioeconomic status at the community level in these areas. Low wages, slow job growth, and lack of industry contributed to the financial instability of the community, thus personal financial instability. Even those AIs who were employed did not have paid time off needed for their health care appointments. Inability to take time off from work was associated with the mesosystem/social level and overlapped with the exosystem/physical environment level, particularly when the participant needed travel assistance.

Exosystem/physical environment. Although some participants denied that transportation was a barrier to accessing health care, participants who had to travel the

farthest miles (20 to 45 miles) claimed that lack of transportation was a barrier to access and use of health care. This finding was consistent with another study that included persons in rural NC by Chan, Hart, and Goodman (2006) where they determined that patients in rural areas traveled two to three times greater distance than those from urban areas and this compromised access, particularly for patients with limited income for travel. In this study, tribal connections and social media were used to assist in accessing care for those in need of transportation. Participants denied issues related to safety as barriers such as local crime rates, health care facility building structure, or road conditions.

Macrosystem /policy. The lack of insurance or the lack of adequate insurance was the greatest challenge that affected access to health care for these AI participants. This supported the findings from Nance-Floyd's (2015) unpublished paper. One person might seek medical care where another person may not because of the lack of adequate health insurance. Some health insurance policies only allow for care from certain health care facilities or PCPs. Many people without insurance or the money to pay the co-pay or deductible delayed health care services, which is consistent with barriers to access care listed in Healthy People 2020 (US Department of Health and Human Services, Healthy People 2020, 2015).

Clearly, there was an inter-relationship (reciprocal determinism) within the SEM level for the decision making process for accessing health care among AI in southeastern NC. Accessing health care for the participants in this study was related to availability of the provider, personal schedules (work or school), transportation, money, and insurance.

The decision to access health care for people without insurance or the financial means to pay deductibles or co-pays resulted in a delay in services. This finding was consistent with Spleen, Lengerich, Camocho, and Vanderpool (2014) who found that non-American Indians without health care insurance were more likely to avoid seeking health care. Although several FQHC are available in the area, not all clinics are within a reasonable distance to many of the participants. Provider availability, inconsistency in providers, and office wait times were barriers to accessing health care for these AIs. Providers per population remains low for these underserved areas where participants in this study reside. Failure to have protected time to leave work and seek health care without being penalized created a delay in service. This study's findings were consistent with previous research that found that the lack of primary care providers was a barrier to health care access in rural communities (Jost, 2014; North, McElligot, Douglas, & Martin, 2012; Ziller, Lendarson, & Coburn, 2012).

Research Question 3

(What do American Indians in southeastern NC consider as important factors in their decision making process for choosing to utilize health care services?) The microsystem/individual, mesosystem/social environment, and macrosystem /policy domains interacted during the decision making process for using health care for these AI participants. Below are how the SEM levels were revealed within the text.

Microsystem/individual. These AI participants agreed that using or not using health care services oftentimes was a personal choice (behavior). Participants spoke freely about available health prevention opportunities, yet, some chose not to use the

vaccinations services. The most often reported individual reason to use or not use services was the personal and trusting relationship they had with their primary care provider (PCP). The participants who had health insurance were particularly vocal about their decision to delay services if they did not have a personal and trusting relationship with their PCP. This finding validated Spleen and colleagues (2014) findings from a study with non-American Indians that found a lack of confidence or trust in the provider and poor provider rapport were associated with health care avoidance. Past experiences with the providers and health care facilities, such as hospitals or urgent care facilities, contributed to the personal decision to use certain providers and services or use a different provider or services – even in the absence of health insurance.

Mesosystem/social. Especially when an individual displayed signs and symptoms of illness, family and friends supported the need for the individual to see a primary care provider. Family and friends also influenced which PCP or health care facility would be chosen by the individual.

Macrosystem /policy. There was a connection between the microsystem/individual and the macrosystem/policy level for access and use of health care services in this study. Some participants did not utilize the local, most convenient health providers because of the lack of a personal and trusting relationship with the provider. These findings agreed with those of Smyer and Clark (2011), that trust must be earned for AI people. However, this study did not support that AIs did not trust non-American Indian health care professionals as stated by Cavanaugh, Taylor, Keim, Clutter, and Geraghty (2008), Daher (2012), and Smyer and Clark (2011). Those researchers’

studies were with federally recognized tribes, not with persons from state tribes in NC. The participants in this study voiced having a positive relationship with many providers and they did not identify if the provider was AI or not. A trusting relationship could be established with any caring provider. That finding supported Bell and colleagues (2013) work that revealed that AIs followed a prescribed regimen when they trusted their physician. More specifically, Bell et al., (2013) articulated that there were no statistically significant differences in trust in physician between African Americans, Native Americans and whites.

Various health insurance policies provide autonomy to the individual to choose the hospital or provider. When participants chose to use a certain hospital or provider without adequate insurance or money to pay a co-pay, a few PCPs and all of the hospitals were willing to arrange payments over time. This assisted in the decision making process to access and utilize care for these participants.

Fitting the data within the SEM levels assisted the researcher to make sense of the data. There was interaction between the layers of the SEM or what has been termed by Bandura as reciprocal determinism (Bandura, 2001; Bandura, 2004). This important interaction guided the researcher in assembling the findings from these AI participants on how they perceive illness and make decisions to access and use health care services.

Conclusion

According to these AI participants, having an illness is different than being ill. Illness was described as having one or more medical diagnoses or a history of surgery, having physical signs or symptoms, and having a daily medication requirement. Being ill

was described as a change in physical signs and/or symptoms or lacking the energy or ability to function. These findings supported Nance-Floyd's (2015) unpublished work, *Focused ethnography study to examine current health status of Native Americans in Eastern North Carolina*. The perception of illness for these AI study participants (having a medical diagnosis) facilitated their decision process to seek preventive (primary, secondary, or tertiary) care. Many times, if they did not experience being ill (current signs and symptoms), persons would not begin the decision making process to seek health care.

The decision making process for accessing health care blended with the decision making process for utilizing health care. The decision making process for going to scheduled health events such as for preventive health care reasons was clearer than for unscheduled health events. The following represents how people made decisions to access and use health care for both scheduled and unscheduled events.

Decision Making Process for Scheduled Events

Adequate health insurance coverage influenced the decision for participants to seek out scheduled health care visits. Health insurance coverage provides individuals with multiple options for a primary care provider, and in effect, these participants were more likely to find a suitable provider and build a trusting patient-provider relationship. Below, the decision making process for people with health insurance will be reviewed followed by the process for the uninsured.

People with health care insurance and a PCP. Participants with health insurance and a satisfactory relationship with a primary care provider (PCP) sought

preventive (primary, secondary, and/or tertiary) care. Participants with insurance who did not have a satisfactory relationship with their current PCP, sought a new PCP. People who had both insurance and what they believed to be a satisfactory PCP, yet still without a means of transportation needed for the appointment, sought transportation from family or friends in order to see their provider. For participants with health insurance and the means to pay any necessary copays for health care services, an unsatisfactory patient-provider relationship was the most frequently expressed reason to delay health care treatment.

Although an unsatisfactory or poor patient-provider relationship was the major decision making element for participants who had insurance, it also served as a barrier for those who did not have insurance or the money for services.

People without health care insurance and/or a PCP. Among the study participants, if a person did not have insurance, many times they did not have a PCP. Participants without insurance or a means to pay co-pays or deductibles did *not routinely* access scheduled provider appointments for preventive (primary, secondary, and/or tertiary) care. This finding was similar to research conducted in southeastern NC related to access to oral health care. Wells and colleagues (2010) learned that there was a relationship between poor oral health and access to oral health care related to the cost of services.

While scheduled health care visits may be planned, unscheduled events, as will be discussed in the next section, provide a unique decision making process for AIs in rural southeastern NC.

Decision Making Process for Unscheduled Health Events

The decision making process for accessing and using health care was related to a change in health status as either a) a problem progressively worsened or there was an abrupt change in health status with the perception of a potentially life threatening outcomes (e.g., difficulty breathing, bleeding, pain, or change in activity or ability to function), henceforth called emergencies; or b) a condition perceived as less life threatening, henceforth called non-emergencies. If the health care status was abrupt or life threatening, insured and uninsured participants accessed and used the local hospital emergency department. Participants who had a change in health status sought care depending on personal, social, physical, or policy barriers at the moment the decision was needed.

Delay in services were caused by the interactions of personal, social environment, physical environment, and/or policy barriers. Personal barriers included preference, self-remedies, fear of the unknown, lack of finances or insurance, and dissatisfaction with the patient-provider relationship. Social barriers included work or school schedules, family obligations, provider availability (office hours and wait time), lack of transportation, and lack of insurance. Physical environment barriers included lack of public transportation. Policy barriers were the lack of insurance and lack of access to health care clinics within rural areas.

For less abrupt changes or a progressive change in health status, decisions to access and use health care services were related to the individual's personal barriers. Although many of the participants shared the barriers they experienced, there were major

differences in the way these individuals decided to access and use care. A significant contribution to understanding how AIs in southeastern NC make health care decisions was the decision making process during an unscheduled health event, and how this differed between the participants who had insurance and those who did not.

The following section is a description of the decision making process for people with insurance. Figure 5 represents the Decision Making (DM) Tree for Accessing and Utilizing Health Care - People *with* health care insurance and a PCP. The second section describes Figure 6 which is the Decision Making (DM) Tree for Accessing and Utilizing Health Care - People *without* health care insurance and/or PCP. These DM trees describe how these AI participants decided to access and use health services depending on whether or not they had health insurance.

Decision Making (DM) Tree for Accessing and Utilizing Health Care

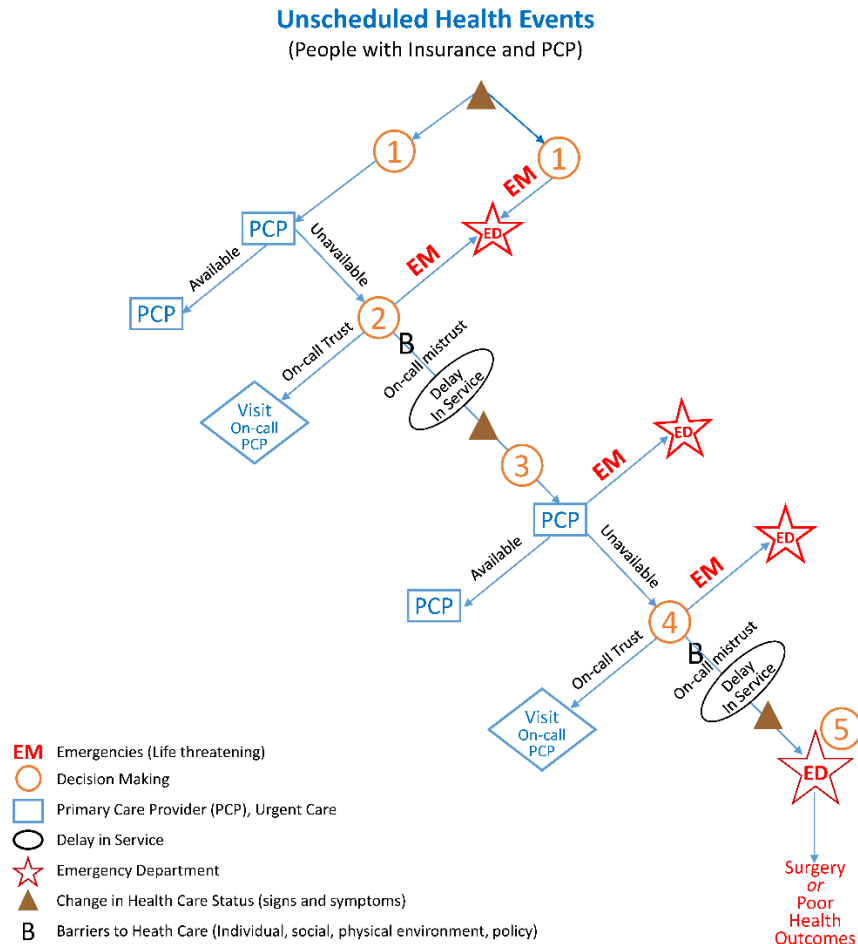


Figure 5. Decision Making Tree for Accessing and Utilizing Health Care. Unscheduled Health Events. People with Health Care Insurance and a PCP. (Produced in part by the Department of Communications; School of Nursing, The University of North Carolina at Chapel Hill, Lee Smith, MA, MSIS, Instructional Designer, February, 2016)

People with health care insurance and a PCP. The Decision Making (DM)

Tree for accessing and Utilizing Health Care - People with health care insurance and a PCP (Figure 5) is used to illustrate the following. This DM tree demonstrates the process for people who had adequate health care insurance and a personal and trusting

relationship with a PCP. There are several levels at which a decision is made. First, there was a change in health status that required the participants to reevaluate the need to seek a health provider. DM level 1 represented if they believed the change to be life threatening, or not. If it was an emergency or life threatening, they sought care at the emergency department (ED). If the change was not life threatening, they called their PCP's office. If their PCP was available, they accessed and used health care services (no delay in services).

If their PCP was not available, the participants had three choices (DM level 2). Participants would first decide to seek health care based on who (which PCP) was available. If an alternative or on-call provider was available with whom they had a previous satisfactory relationship, they would seek care (no delay in services). If they did not have a good relationship with the on-call provider, they would access and use the local emergency department if they were unable to tolerate the symptoms of being ill. Or, they did not access or use care (delay in services).

If the signs and / or symptoms of illness continued or became worse, they would either decide (DM level 3) to go to the ED for abrupt changes or health issues they could no longer tolerate, or they would contact their PCP (no delay in services). If their PCP was not available, the participants had three choices (DM level 4) which was the same as the DM level 2, yet now, with a delay in services. The decision making cycle continued until the change of health status became unbearable and required an abrupt ED visit. Unless the change in health status was considered an emergency by the participant, a delay in services occurred when participants did not feel satisfied with the PCP or the

patient-provider relationship. It is important to note, however, that in times of abrupt changes in health conditions or emergencies, there were no delays in treatment for the insured. Next, the DM tree for people without insurance is reviewed.

Decision Making (DM) Tree for Accessing and Utilizing Health Care

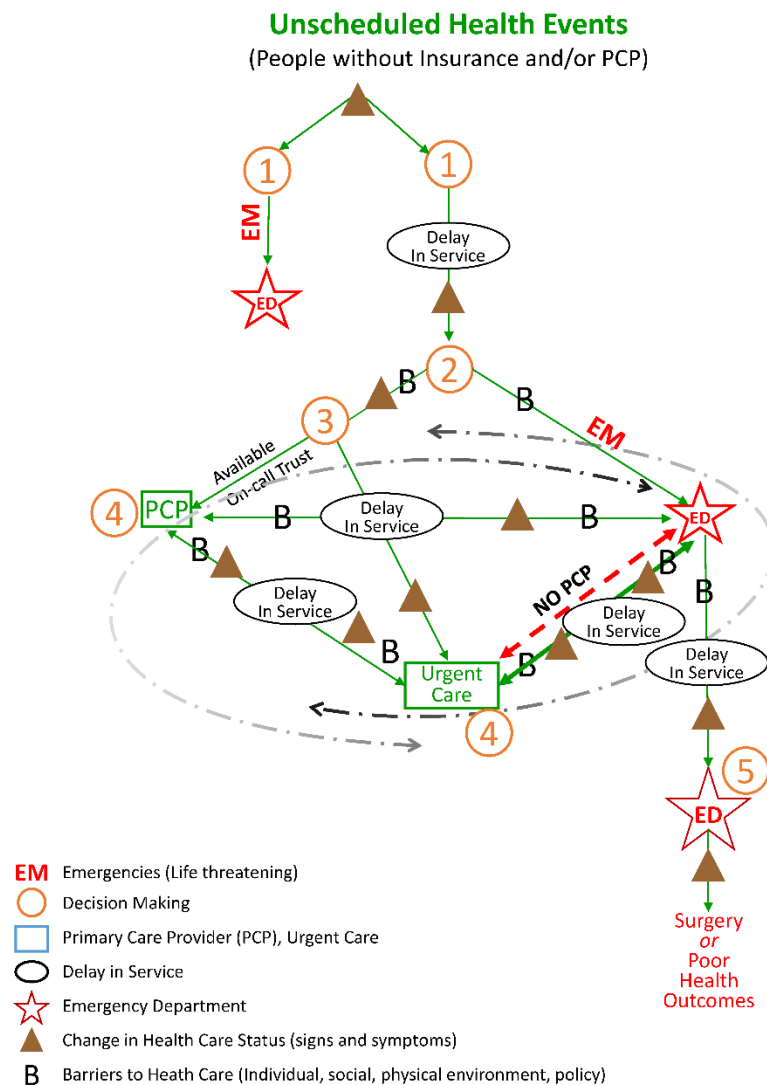


Figure 6. Decision Making Tree for Accessing and Utilizing Health Care. Unscheduled Health Events. People without Insurance and/or PCP. (Produced in part by the Department of Communications; School of Nursing, The University of North Carolina at Chapel Hill, Lee Smith, MA, MSIS, Instructional Designer, February, 2016)

People without health care insurance and/or a PCP. The Decision Making (DM) Tree for accessing and Utilizing Health Care - People without health care insurance and/or PCP (Figure 6) is used to illustrate the following. For the participant who either had a lack of health insurance, a lack of adequate health insurance, lack of money to pay the co-pay or deductible costs, the decision to access or use health care was delayed. The decision making process for accessing and using health care was related to if the change in health status was a) an emergency (life threatening), or b) perceived as non-emergent (less life threatening). For participants who experienced an emergency, the decision (DM level 1) was a direct visit to the ED. For non-emergencies, there was a delay in services (DM level 1). Some participants attempted additional self-remedies (delay in services) until they could no longer tolerate the experience of being ill. As the signs and symptoms of illness worsen, DM level 2 provides a framework for decision making. Participants would decide (DM level 2) to either go to the ED for an emergency, or visit a non-emergency provider. Depending on their barriers experienced they would either contact (DM level 3) a PCP, or seek (DM level 3) treatment at an urgent care. If a trusted PCP was available and payment could be negotiated, they sought care at the trusted PCP. If a trusted PCP was not available, they sought care at the urgent care provider.

Many times, there were delays in services due to barriers, particularly payment plan for services, and provider office hours. Once persons received health care for non-emergencies, if a follow-up appointment was needed or if the condition or health status changed, DM level 4 was launched. They made the decision (DM level 4) to return to the

PCP, urgent care, or the ED depending on whether the situation was an emergency, non-emergency, and the barriers that came into play. The most frequently voiced barriers for these participants were the lack of adequate insurance or the lack of money for the treatment. These barriers constituted another layer of delayed services. Eventually, an emergency could occur. As noted before, with an emergency participants reported that they sought treatment in the ED. Not having insurance or the inability to pay for services was the greatest barrier to access and using health care services. The people without insurance may not have had a PCP, and thus did not have an opportunity to have a relationship, satisfactory or unsatisfactory, with a provider. In addition to adequate health insurance, having a trusted patient-provider relationship is essential for timely treatment. Timely treatment awards better health outcomes.

The findings in this study supported the US Department of Health and Human Services, Healthy People 2020 (2015) determinants of health to include local, state, and federal health policies, social norms/attitudes, social support, socioeconomic conditions, job opportunities, wages, transportation, lack of available health services, health care costs, and inadequate insurance coverage, as factors that influence personal behavior. In this study, these determinants of health specifically influenced the decision making processes used by these AIs to access and use health care services. Nurses are professionally accountable for providing options to reduce these factors in order to promote better patient outcomes. In fact, the Institute of Medicine (IOM) charged nurses to be change agents and leaders in health care (IOM, 2011). The following

recommendations are different approaches nurses can employ to improve health outcomes for American Indians in southeastern NC.

Recommendations

In *The future of nursing: Leading change, advancing health*, the IOM recommended that nurses assume leadership positions across *all* levels within the health care delivery system and that public, private, and government health care decision makers should include nurses in key leadership positions (IOM, 2011). Nursing is guided by holistic understanding of individuals. This holistic understanding of individuals fosters a trusting patient-nurse relationship, a theme especially important for American Indians in this study. Historically, nurses have been thought of as trustworthy. In fact, with the exception of 2001 when firefighters were the most trusted professionals, the Gallup poll has consistently listed nurses as the most trusted professional since nursing was added to the Gallup poll list in 1999 (Gallup, 2016; Jones, 2010). Nurses are perfectly poised to lead innovations for the AI people. For improved health outcomes and fewer negative consequences associated with lack of health care for this group, nurses need to strategize with AI community leaders, educators, economic planners, and government officials to plan health promotion strategies and to create community programs that can change health outcomes for this population. The following are recommendations for nursing research, practice, policy advocacy, and education.

Nursing Research

Nursing research is critical for the American Indian (AI) population. In the past decade, research funding that included the AI population has slowly increased, yet

current nursing research remains scarce, particularly related to AIs in southeastern NC. Therefore, the findings of this study are an important contribution to the body of knowledge. Nonetheless, more research is needed.

Although this study successfully used the layers of the SEM to understand AIs perception of illness and decision making processes for accessing and utilizing health care, using other theoretical frameworks to guide work with AI populations could be an important strategy. Since trust and trusting relationships were needed for access and use of care services by these AI participants, nursing theories could be considered as a guide. For example, Swanson's Caring Theory would be an appropriate option. Swanson's theory claims that nurses use informed caring for the well-being of others (Swanson, 1993). Her theory contains five components, namely, a) maintaining belief, b) knowing, c) being with, d) doing for, and e) enabling to produce the intended outcome – client well-being (Swanson, 1993). This theory would be particularly useful while working with AIs because *caring* will assist in building relationships (Tonges & Ray, 2011) that AIs believe to be necessary. Tonges and Ray (2011) reported that interventions guided by Swanson's Caring Theory built stronger patient-nurse relationships, which resulted in better Press Ganey scores for patient satisfaction, and health outcomes for patients in North Carolina – many of these patients are referred from southeastern NC.

Another example of a theory that might be used to guide AI research is the Social Cognitive Theory (SCT) developed by Bandura. Bandura believed that if a person was motivated, through observation and reproduction, people would retain knowledge and behaviors (Bandura, 2001). He used a triad of concepts, namely, (a) behavioral factors

(b) environmental factors and (c) personal factors that constantly intermingled (reciprocal determinism) to facilitate self-regulation of one or more interventions within one or more variables at any given time (Bandura, 2001; Simons-Morton, McLeroy, & Wendel , 2012).

The SCT has been most successful in health promotion and prevention of diseases (Simmon-Morton et al., 2012), an outcome sorely needed with the AI population. Self-regulating methods can be either behavioral or cognitive. A behavioral focus is on managing stimuli and reinforcement (Simmon-Morton et al., 2012). Cognitive methods use mental reminders or knowledge based facts in the behavior processes (Simmon-Morton et al., 2012) to promote health. Additionally, important self-regulating motivational factors are goal setting, self-efficacy, and perception of expected outcomes (Bandura, 2001; Bandura, 2004; Simmon-Morton et al., 2012). The SCT and the SEM have been used successfully in research with AI populations. The SEM is specifically useful when an understanding of political factors (policy change) are needed. These theories and frameworks can be used to guide qualitative, quantitative and mixed-methods research, all of which could be used to understand how to *best* care for the AI population.

Efforts to maximize the knowledge of AI health among health care providers is needed in southeastern NC. To enrich understanding of their perception of illness and decision making processes for accessing and using health care, this study should be repeated in other areas of southeastern NC where AIs reside. Particularly, studies that focus on AIs who are uninsured are needed. The decision making trees for access and

using care for unscheduled events should be tested throughout rural southeastern NC in all populations so that health determinants that influence decision making for others in these areas can be identified for future planning. These decision trees could be useful for providers and policy makers when seeking to promote improved health outcomes for these persons.

For quantitative research, tools that are AI appropriate will be needed to measure specific constructs. For example, this study reported that poor patient-provider relationships resulted in a lack of trust in the provider and was a major cause of delay of services for these participants. To measure trust in health care providers, for example, the General Trust in Physician scale was successfully used in eastern NC with AAs, NAs, and whites (Bell et al., 2013). Another example was the Medical Mistrust Index (MMI) has been a reliable tool (Cronbach's $\alpha = 0.76$) for other vulnerable populations (Brandon, Isaac, & LaVeist, 2013). Yet, the MMI has not been tested in the AI population. Testing this tool or the General Trust in Physician scale in the rural AI population in southeastern NC would be important to advance knowledge in this area.

Typically, in quantitative research, efforts to promote generalizability include efforts to enhance heterogeneity, for example, making even the convenience sample more purposeful (Polit & Beck, 2012). Johnson, Wilfert, and the FOCUS Workgroup, (nd) describe a strategy, cluster sampling, that begins with a qualitative data collection method, a face to face interview. This strategy is also referred to as a "30 x 7" survey (Johnson et al., nd, p. 2). The larger geographical area (southeastern NC) could be divided into 30 smaller clusters; next, seven (7) people or households would be randomly chosen and

questioned within each of the 30 clusters to yield a total of 240 participants (Johnson et al., nd). This method would begin as a qualitative interview process which has been historically more appealing to the AI population. AI are natural storytellers and prefer to engage in communication rather than long questionnaires or surveys. A method such as the 30 x 7 could yield the sample numbers that many positivists could view as more robust. Furthermore, research that adds community partners such as community-based participatory and faith-based approaches would be culturally appropriate and recommended for AIs in southeastern NC.

Additionally, collaboration with social scientists, economists, policy makers, and those in other health disciplines in targeted interprofessional research is needed to change the health outcomes for AIs. The Institute of Healthcare Improvement's (IHI) Triple Aim for Populations (2015) is focused on high-risk, high-cost populations to reduce disparities and/or inequities, to improve the health of a population (IHI, Triple Aim for Populations, 2015). The Centers for Medicare and Medicaid Services (2015) continues to offer models that focus on population health management by creating partnerships between the patient and the practice through better coordination of care (Centers for Medicare & Medicaid Services, 2015). Nursing should lead in these efforts and influence community practice.

Nursing Practice

Community-based participatory researchers and/or faith-based researchers could test interventions for health promotion and health prevention for the AI population in rural southeastern NC. One example is a nurse-driven mobile care program. First, a

feasibility study is needed to address the pros and cons of offering a free standing care unit within the tribal centers or a mobile care free clinic for tribal communities in southeastern NC. Mobile care units can provide emergency care, diagnostic studies, or primary care for acute and chronic illnesses. At the time of this writing, The Mobile Health Map (2016) lists 723 mobile care units in the US, each seeing on average 3,515 visits per year with a return on investment for preventive services of 1:14. The use of primary care mobile units is growing in other states much faster than in NC.

The literature supports using mobile units for value based care. For example, the return of investment was reported by Oriol et al., (2009) as \$36.00 and \$30.00 by the Mobile Health Map (2013) for every dollar spent for preventive services. A savings of \$1.6 to \$2.1 million from January 2010 through June 2012 from monitoring hypertension and reducing emergency room visits was reported by Song, Hill, Bennet, Vavasis, and Oriol (2013). More locally, Wayne Memorial Hospital in NC reported their WATCH program, a nurse-driven program, has reduced emergency department visits and reported a return on investment in 2014 of \$7.13 for every dollar spent (WATCH, 2014).

WATCH also testified in their 2014 Annual Report that 10,586 visits were made, 9,414 patients received a 30-day supply of medications, that the retail value of medications provided was \$2,791,531.00, and that \$538,084 in free laboratory expenses were given (WATCH, 2014). Establishing a free clinic in tribal centers and a free mobile clinic in neighborhoods would assist these Americans in accessing health care in a timely manner. The community partnerships would address the IHI triple aim to improve the patient experience of care by building relationships in the community, enhancing the patient-

provider relationship, and by providing competent care in a timely manner while reducing costs (IHI, Triple Aim for Populations, 2015). The Institute of Medicine (2011) report *The future of nursing: Leading change, advancing health* states that nurses should practice to the full extent of their education and licensing and the IOM should facilitate such practices. Overall, North Carolina lags behind most states. Nurses should be leaders in establishing these community relationships and free clinics. Policy change is needed.

Nurses as Policy Advocates

Nurses should advocate for policy change regarding adequate health insurance of all AIs and for free clinics in AI communities. Nurses should meet with local and state legislative members and inquire about delayed legislature. For example, Rural NC Senate Bill 533 was introduced on April 1, 2013 to create a taskforce to study the expansion of telemedicine particularly for people with chronic illnesses. NC House Bill 704 was introduced on April 11, 2013 which would fund studies for access to health, reduce health disparities and provide efficient care using telemedicine. At the time of this writing, according to the NC legislative website (North Carolina Legislative, 2016), both bills quickly went to the Rules and Operation committee where they remain functionally inactive. No research is found on the NC legislative website related to these bills, potential legislative ideas, or any ongoing research related to access to health care. It is time for nurses to get involved in policy change.

States around the nation model success stories for NC nurses to follow. For example, California and Kentucky have public laws for mobile care units. In California the Health and Safety Code Section 1765.101-1765.175 bill also known as the Mobile

Health Care Service Act (California Code, 2014) and in Kentucky 902 KAR 20:275 Mobile health services (Kentucky Code, 2014) use mobile units to provide health care services outside a mortar and brick facility. These mobile units have the same capacity to assess and treat all patients for acute and chronic illnesses (California Code, 2014; Kentucky Code, 2014). In California, telecommunication devices are required in the mobile units (California Code, 2014). All health care licensees using mobile units must abide by the same policies and procedures that other licensed health care facilities provide (California Code, 2014; Kentucky Code, 2014). North Carolina can use one of these laws as a model and develop a specific law to meet the needs of our rural populations. Nurses could be proactive in promoting this.

Nursing Education

Nurses should open conversations with other health providers and assist in identifying ways to develop stronger patient-provider relationships. As part of the interprofessional educational (IPE) team, nurses should model how to build trusting relationships in the AI communities to students and current providers. Nurse educators must assert themselves in the role of change agent for academic pedagogical shifts to include creating IPE courses that include clinical immersions to build better communication and relationships within teams - but more importantly with patients.

Nursing education curricula that concentrate on administration and health care systems education can contribute substantially to research on access to care, policy analysis, cost analysis, and advocate for policy change. Nurse administrators and leaders could manage the daily operations of the free clinic (business). Doctoral nursing practice

(DNP) students could specialize in family health with a specialty in community health practice for AI health and become a key stakeholder as a community liaison. As part of the interprofessional (IP) team, these DNP providers will be the future providers of the nurse-driven community free clinics and mobile units in rural America.

Educational grants to support AI nurses from these communities could be sought by graduate educational programs to help these AI nurses study and then return to their communities to serve in leadership and administrative roles to support population health management. In addition, AI nurses could study to become nurse practitioners, nurse educators, and nurse scientists. Each recommended nursing role could be paired with the individual career goals of the AI nurses who live in these communities. These educational grants will provide an opportunity for program sustainability by training AI nurses to return to their home communities for their professional practice.

Limitations

While this qualitative approach to research has many strengths, limitations to this line of inquiry exist. The lack of trust in non-AIs by AIs has been well documented (Cavanaugh et al., 2008; Daher, 2012; Smyer & Clark, 2011). In a report by the National Congress of American Indians Research Center, (2012), AI researchers explain that some AIs had been hesitant to participate in any research. Historically, AIs question non-AIs' objectives. Several gatekeepers were needed for the large geographic area. One gatekeeper made introductions to other gatekeepers in specific areas. Developing trusting relationships with new gatekeepers in a short timeframe delayed data collection. Data collection during the Christmas and New Year's holidays may have influenced

participant availability. The study did not include AIs from all of the tribes in southeastern NC. Given the small sample, there was an inability to infer to larger populations. Many of the participants were elderly with Medicare. There were few males participants.

Summary

American Indians have suffered socially and economically throughout American history which has resulted in poor health outcomes for this group that includes many chronic illnesses. The cost of these has crippled AI people and has become devastating to the economy. Most of AIs in NC live in rural, economically drained areas where access to health care is difficult. Historically, little effort had been devoted to understanding why some AIs access and use health care while others do not, yet there are huge health inequities for this population. Due to an increase in health care costs, the need for additional health care providers, disabilities from chronic illness faced by this marginalized group (AIs), and a national debt in the trillions, this research was an essential addition to the body of knowledge. It has the potential to inform policy, education, and research, as well as nursing and interprofessional education practices.

The purpose of this study was to understand the perceptions and experiences of illness among American Indians in southeastern NC and to describe their decision making processes when accessing and using health care services. Focused ethnography methodology was used to understand these experiences and decision making processes. The SEM assisted in placing the inductive analysis into context.

According to these AI participants, illness was described as a noun (medical diagnosis) and being ill was described a verb (signs and symptoms). The decision making process for accessing and using health care intermingled. There were elements from all of the SEM levels that influenced the decision making process. Yet, two factors were more prominent than the others. First was adequate insurance and second was a relationship with the provider. If either of these factors were missing, there was a delay in health care services for these AIs. They would, however, seek care in an emergency. Many claimed that they, or others in their community, do not have adequate health insurance. Having access to health care from a trusted provider was critical for AIs in southeastern NC.

Recommendations for future research, practice, and education include community-participatory or faith-based research using SEM or the SCT with Swanson's Caring Theory. Nurses are the most trusted profession and are duty bound to provide equitable care. Nurses can lead practice change for the AIs in southeastern NC. Mobile care units have the potential to provide emergency care, diagnostic studies, or primary care for acute and chronic illnesses to this marginalized population. Studies have shown positive patient outcomes and favorable financial return on investment from the mobile care unit. Other states have public laws supporting mobile care services for the provision of primary care. Mobile care units with telemedicine staffed with nurse practitioners could provide primary care to rural communities in NC in a cost effective way.

Nurse scientists can contribute to policy change and implementation at multiple levels. Health outcomes measurements will be needed for policy change. Nursing

research, practice and education can support efforts to meet Health People 2020 goals for access to health services and other objectives related to preventing and managing chronic illnesses for this marginalized group in order to improve health outcomes and life for this population.

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APPENDIX A

DEMOGRAPHIC QUESTIONNAIRE

Research Title: *A qualitative study to understand the perception of illness and the decision making process for accessing and utilizing health care for American Indians in southeastern NC.*

Demographic questions: Please write your answer to items on the line provided, and circle your answer choice for the other items.

1. What year were you born? _____
2. Do you identify as
Male or **Female**
3. Do you work outside the home?
Yes or **No**
4. If you answered “yes” to question 3, do you work (are you considered by your employer)
Part-time or **Full-time**
5. Do you have health care insurance?
Yes or **No**
6. If you answered “yes” in question 5, please circle your choice about your health care insurance.
Private
Medicare
Medicaid
Affordable Care Act (Obamacare)
Other _____
7. Approximately how many miles do you travel (one way) to see a health care provider?

8. What is the highest degree or level of school you have *completed*? (**circle your choice**)
 - a. **No school completed**
 - b. **Grade 1-11 ____** (specify the highest grade completed, please).
 - c. **Grade 12 with a diploma or GED**
 - d. **Some college (no degree)**
 - e. **Associate’s degree**
 - f. **Bachelor’s degree**
 - g. **Master’s degree**
 - h. **Professional degree beyond bachelors (for example: MD, DSS, DVM, LLB, JD)**
 - i. **Doctorate degree (for example: PhD, EdD)**

APPENDIX B

FOCUS GROUP GUIDE

Using Sharmen Simon's *How to Conduct a Focus Group* and Barbour's *Doing Focus Groups* as a guide, three (3) to four (4) focus groups, each with 5-6 participants will be conducted for approximately 60 minutes.

Title: *A qualitative study to understand the perception of illness and the decision making process for accessing and utilizing health care for American Indians in southeastern NC.*

The purpose of this study is to understand how American Indians in southeastern NC perceive and experience illness and how they describe their decision making process in regard to access and utilization of health care.

Research Questions

1. How do American Indians in southeastern NC describe illness or being ill?
2. What do American Indians in southeastern NC consider as important factors in their decision making process for accessing health care?
3. What do American Indians in southeastern NC consider as important factors in their decision making process for choosing to utilize health care services?

Inclusion criteria: Self-identified American Indians living in southeastern NC, English speaking adults ages 18 and older who agree to participate in a focus group or an interview.

The group will meet in an enclosed room for privacy in a local public place that is chosen by the participants (for example, one of the public libraries southeastern NC). During recruitment, the participant(s) will be given several local library. The participants will be facing each other to enhance open discussion among the participants. The researcher will draw a map of the room or take a photograph of the empty room and add to the field notes.

(Once informed consent is obtained from each participant and consent is given to record the interview, I will begin by stating the following. At any time during the interview, if any participant asks that the recording be stopped, it will be and documented in the transcription and field notes)

Researcher script: Thank you for your time and for you sharing your personal experiences today. I am conducting a study to understand how you define illness and to understand how you make decisions on when, where, and how you access and use health care. You signed the consent form earlier and agreed to have the interview taped. Is that correct?

(Wait for the answer “yes” from all participants before completing the directions and asking the following questions)

I’m interested in understanding when you believe you are sick or ill and when you believe you are well. I’m interested in how you make a decision on when, where, and how you go see a health care provider. Basically, I want to understand how you make decisions on when and where to go to obtain health care and what, if any, differences there may be as to why some people seek a provider and others do not (transportation, safety, or other reasons). I would like for you talk to each other in a conversational manner. It’s important that everyone has an opportunity to express him or herself freely. Let’s give everyone the chance to share their thoughts in the conversation by talking one at a time, please. Please make sure that your cell phone is off or on silent. I will be here mostly to listen and gently guide the conversation to keep us on track. Let’s also remember that everything that is said in this room is confidential and that your name will not be identified with anything that you may say or do in this room. Again, I thank you for your time. Do you have any questions? Let us begin.

1. How do you feel about your current health?
2. What do you consider to be “good health”?
3. What do you consider to be “poor health”?
4. How, if at all, would you like your health to be different 5 years from now?
5. When was the last time you felt really sick?
 - a. Can you tell me more about that?
6. How do you make the decision to go see a health care provider?
 - a. Can you tell me about the last time you did this?
 - b. If yes→How did you decide where to go?
 - c. What happened next?
 - d. Who else, if anyone, did you talk to about it?
 - e. If didn’t go to provider→Can you tell me more about why you chose not to?
 - f. What, if anything, would you like to be different next time?
7. What, if anything, gets in the way of your using the clinic/hospital/health department?
 - a. Insurance?
 - b. Transportation?
 - c. Travel?
 - d. Safety?
 - e. Work hours?
 - f. Other?
8. How do you feel about going to the clinic/hospital/health department?
 - a. What, if anything, do you wish could be different?

9. Talk to me about how you feel about your health care providers?
 - a. Trust?
10. If someone asked you for advice on where to go for health care, what might you tell them?
11. If someone asked you for advice on who to see for health care, what might you tell them?
12. Why do you think that some people go to the clinic/Dr/ED/other while others don't go?
13. Is there something else you'd like to add?

Upon completion, field notes taken during the interviews will be added to the researcher journal.

The digital recording will be transmitted within 24 hours via a secure line to the contracted transcription company for verbatim transcription. Audio and transcription will be validated by the PI.

APPENDIX C

INTERVIEW GUIDE

Using Dr. William Marsiglio's *Conducting Qualitative In-depth Interviews* as a guide, semi-structured interviews with four (4) to five (5) participants will be conducted for approximately 60 minutes per interaction.

Title: *A qualitative study to understand the perception of illness and the decision making process for accessing and utilizing health care for American Indians in southeastern NC.*

The purpose of this study is to understand how American Indians in southeastern NC perceive and experience illness and how they describe their decision making process in regard to access and utilization of health care.

Research Questions

4. How do American Indians in southeastern NC describe illness or being ill?
5. What do American Indians in southeastern NC consider as important factors in their decision making process for accessing health care?
6. What do American Indians in southeastern NC consider as important factors in their decision making process for choosing to utilize health care services?

Inclusion criteria: Self-identified American Indians living in southeastern NC, English speaking adults ages 18 and older who agree to participate in a focus group or an interview.

(Once informed consent is obtained from each participant and consent is given to record the interview, I will begin by stating the following. "At any time during the interview, if any participant asks that the recording be stopped, it will be and documented in the transcription and field notes".)

Researcher: Thank you for your time and for you sharing your personal experiences today. I am conducting a study to understand how you define illness and to understand how you make decisions on when, where, and how you access and use health care. You signed the consent form earlier and agreed to have the interview taped. Is that correct?

(Wait for the answer "yes" before beginning with the following questions)

I'm interested in understanding when you believe you are sick or ill and when you believe you are well. I'm interested in how you make a decision on when, where, and how you go see a health care provider. Basically, I want to understand how you make decisions on when and where to go to obtain health care and what, if any, differences there may be as to why some people seek a provider and others do not (transportation, safety, or other reasons). I would like for you to talk to in a conversational manner. I will ask that you please make sure that your cell phone is off or on silent. I also want you to know that everything that is said is confidential and that your name will not be

identified with anything that you may say or do. Again, I thank you for your time. Let us begin.

14. How do you feel about your current health?
15. What do you consider to be “good health”?
16. What do you consider to be “poor health”?
17. How, if at all, would you like your health to be different 5 years from now?
18. When was the last time you felt really sick?
 - a. Can you tell me more about that?
19. How do you decide when to go see a health care provider?
 - a. Can you tell me about the last time you did this?
 - b. If yes→How did you decide where to go?
 - c. What happened next?
 - d. Who else, if anyone, did you talk to about it?
 - e. If didn’t go to provider→Can you tell me more about why you chose not to go?
 - f. What, if anything, would you like to be different next time?
20. What, if anything, gets in the way of your using the clinic/hospital/health department?
 - a. Insurance?
 - b. Transportation?
 - c. Travel?
 - d. Safety?
 - e. Work hours?
 - f. Other?
21. How do you feel about going to the clinic/hospital/health department?
 - a. What, if anything, do you wish could be different?
22. Talk to me about how do you feel about your health care providers?
 - a. Trust?
23. If someone asked you for advice on where to go, what might you tell them?
24. If someone asked you for advice on who to see, what might you tell them?
25. Why do you think that some people go to the clinic while others don’t go?
26. Is there something else you’d like to add?

Upon completion, field notes taken during the interviews will be added to the researcher journal.

The digital recording will be transmitted within 24 hours via a secure line to the contracted transcription company for verbatim transcription. Audio and transcription will be validated by the PI.

APPENDIX D

CONFIDENTIALITY AGREEMENT

University of North Carolina at Greensboro

RESEARCH CONFIDENTIALITY AGREEMENT FOR RESEARCH INVOLVING HUMAN PARTICIPANTS

I, _____, have agreed to assist Betty Nance-Floyd with the research project entitled *A qualitative study to understand the perception of illness and the decision making process for accessing and utilizing health care for American Indians in southeastern NC*. IRB number: 15-0435.

I agree not to discuss or disclose any of the content or personal information contained within the data, audiotapes, transcriptions or other research records with anyone other than the Principal Investigator, Betty Nance-Floyd, the Faculty Advisor, Dr. Robin Bartlett, or in the context of the research team. I agree to maintain confidentiality at all times and to abide by the [UNCG Policy and Procedure for Ethics](#) in Research and the [UNCG Policy on the Protection of Human Subjects in Research](#).

Date: / / _____

Signature

Betty Nance-Floyd, Principal Investigator To be completed by all members of the research team with access to personal data on human research participants.

File a copy with the PI.

APPENDIX E

RECEIPT FOR CASH

Receipt for demographic questions and semi-structured interview participants

I have received \$10.00 cash from Betty Nance-Floyd, Principal Investigator, for participating in a researched project named *A qualitative study to understand the perception of illness and the decision making process for accessing and utilizing health care for American Indians in southeastern NC.*

Print Name _____

Signature _____ Date _____

Receipt for demographic questions and focus group participants

I have received \$10.00 cash from Betty Nance-Floyd, Principal Investigator, for participating in a researched project named *A qualitative study to understand the perception of illness and the decision making process for accessing and utilizing health care for American Indians in southeastern NC.*

Print Name _____

Signature _____ Date _____

Receipt for attending a confirmation meeting related to data gathered

I have received \$5.00 cash from Betty Nance-Floyd, Principal Investigator, for participating in the a research project named *A qualitative study to understand the perception of illness and the decision making process for accessing and utilizing health care for American Indians in southeastern NC.*

Print Name _____

Signature _____ Date _____

Receipt for gatekeeper

I have received \$50.00 cash from Betty Nance-Floyd, Principal Investigator, for providing gatekeeper services in a research project named *A qualitative study to understand the perception of illness and the decision making process for accessing and utilizing health care for American Indians in southeastern NC.*

Name _____

Signature _____ Date _____

APPENDIX F

GATEKEEPER TELEPHONE RECRUITMENT SCRIPT

Script for American Indian Gatekeeper to invite American Indians in southeastern NC to recruitment meeting

Hello _____, I am _____. I am calling to tell you about an exciting opportunity. A friend of mine, Betty Nance-Floyd, is a PhD nurse research student at the University of North Carolina at Greensboro. She is studying how American Indians living in southeastern North Carolina think about illness and how we make decisions on when and where we go for health care. Basically, she wants to understand how you make decisions on when and where to go to obtain healthcare and what, if any, differences there may be as to why some people seek a provider and others do not.

If you agree to participate in her study, she will first ask you questions with a paper survey. Then you will be asked to participate in a one-on-one interview *or* a group meeting at a time and location of your choice. If you agree to an interview or group meeting, the interview or the group meeting should last about 60 minutes. Ten (10) dollars cash will be given to you if you participate in her study. You will also be invited to a follow-up gathering once she has completed the study. She wants to confirm what she learned from you before she tells other people. She would like to tell you about the study at a meeting at the _____ library on _____ at ____ PM. I'll be at the meeting, too. The meeting will be held in room _____. Would you be willing to attend this meeting? [If answers yes] We will call you to remind you of the meeting the day before. Thank you. Good bye.

[If answers no] Thank you anyway. Good bye.

Approved IRB
11/23/15

APPENDIX G

GATEKEEPER FACE-TO-FACE RECRUTIMENT SCRIPT

Script for American Indian Gatekeeper to invite American Indians in southeastern NC to recruitment meeting

Hello _____, I am _____. I want to tell you about an exciting opportunity. A friend of mine, Betty Nance-Floyd, is a PhD nurse research student at the University of North Carolina at Greensboro. She is studying how American Indians living in southeastern North Carolina think about illness and how we make decisions on when and where we go for health care. Basically, she wants to understand how you make decisions on when and where to go to obtain healthcare and what, if any, differences there may be as to why some people seek a provider and others do not.

If you agree to participate in her study, she will first ask you questions with a paper survey. Then you will be asked to participate in a one-on-one interview *or* a group meeting at a time and location of your choice. If you agree to an interview or group meeting, the interview or the group meeting should last about 60 minutes. Ten (10) dollars cash will be given to you if you participate in her study. You will also be invited to a follow-up gathering once she has completed the study. She wants to confirm what she learned from you before she tells other people. She would like to tell you about the study at a meeting at the _____ library on _____ at ____ PM. I'll be at the meeting, too. The meeting will be held in room _____. Would you be willing to attend this meeting? [If answers yes] We will call you to remind you of the meeting the day before. Thank you. Good bye.

[If answers no] Thank you anyway. Good bye.

Approved IRB
11/23/15

APPENDIX H

CONSENT

Nance-Floyd 11-22-2015

UNIVERSITY OF NORTH CAROLINA AT GREENSBORO
CONSENT TO ACT AS A HUMAN PARTICIPANT
IRB number: 15-0435

Project Title: *A qualitative study to understand the perception of illness and the decision making process for accessing and utilizing health care for American Indians in southeastern NC.*

Betty Nance-Floyd (PhD student), Principal Investigator and Dr. Robin Bartlett, Dissertation Chair

Participant's Name: _____

What are some general things you should know about research studies?

You are being asked to join a research study. Joining this study is your choice. Research studies find out new things. These new things may help people in the future. This study may not help you right now. You may choose not to join. If you decide to join, you may stop being in the study, for any reason, at any time. There will be no harm to you if you stop being in the study. It will not change your relationship with the University of North Carolina (UNC) at Greensboro, the person that invited you to this meeting, or me.

Next, I am going to review the details about this study. It is important that you understand these details so that you can make the best choice for you about whether to join or not. If you have any questions about this study, you may ask me. My contact information is below. If you decide to join the study, you may sign this consent form. You will be given a copy of this consent form.

What is the study about?

Many American Indians suffer long-term illnesses like heart disease, diabetes, and cancer. There is a strong link between these illnesses and how, when, and where you see a health care provider. I'm interested in understanding when you believe you are sick. I'm interested in understanding when you believe you are well. I'm interested in how you make a decision about your health care. I want to understand the relationship you have with your health care providers.

Why are you asking me?

I am interested in studying the access to health care for American Indians age 18 to 65 years old in southeastern North Carolina. I am inviting you because you are English speaking, a self-identified American Indian living in southeastern North Carolina and you are 18 years old or older.

What will you ask me to do if I agree to be in the study?

If you join my study, I will ask you to answer general questions about yourself on a paper survey. I may ask you to join a one-on-one interview or a group meeting. You may agree to answer only the paper survey if you like. If you agree to participate, you will choose the time of the meeting. You will also choose the meeting place from a list of county library locations. If you choose a one-on-one meeting, you may choose to meet over the telephone. If you join a group meeting or a one-on-one meeting, I will ask you things like what illness means to you. I will ask you what you experience when you are ill. I will ask you how you make your decisions about when to go to get health care. I will ask you how you make decisions about where to go to get health care. I will ask you about the relationship you have with your health care providers. The one-on-one interview or the group meeting will last about 60 minutes. You will also be invited to join a follow-up gathering at the end of the study. You do not have to attend the follow-up gathering to join the study.

Is there any audio/video recording?

With your okay, I will audio record what you say. I will also take written notes during the interview or group meeting. The audio recording is to make sure that I hear what you say correctly. The audio recording will be used to type up what you say. I will review the typed words later. If you choose not to be audio recorded, I will only take written notes. I can turn off the recorder anytime you ask. You can leave the interview or the group meeting at any time. Because your voice will be potentially identifiable by anyone who hears the tape, your confidentiality for things you say on the tape cannot be guaranteed although the researcher will try to limit access to the tape as described below.

What are the risks to me?

If any of the questions make you uncomfortable, you may choose not to respond. There is little chance that your private information will be known by others outside of the meeting. However, there is a chance that someone might hear a recording. That person may know who you are and hear what you say. I will do everything I can to avoid anyone from hearing the audio recording. The audio recording will be stored in a secure place that is password protected at The University of North Carolina at Chapel Hill. The people who will help me type the words from the audio recording will sign a privacy form.

We are taking actions to prevent anyone hearing or seeing your private information. I will use separate secure places at UNC-Chapel Hill to store the audio recordings and the typed information. Any papers with your signature or name will be stored in a locked filing cabinet in Dr. Robin Bartlett's office at UNC-Greensboro. I will use trusted typing companies or a trusted researcher helper to type the words from the audio recordings. The Institutional Review Board at UNC at Greensboro has decided that joining in this study causes little risk to you.

If you have questions or concerns, please contact Betty Nance-Floyd at b_nancef@uncg.edu or cell number 910-990-0887. You may also contact Dr. Robin Bartlett (dissertation chair) at rbartle@uncg.edu or office number 336-334-5840. If you have any concerns about your rights, how you are being treated, concerns or complaints about this study, or about how this study may help you or cause risk to you, please contact the Office of Research Integrity at UNC Greensboro toll-free at 855-251-2351.

Are there any benefits to society as a result of me taking part in this research?

It is my hope that the study will help me to understand what being ill means to American Indians in southeastern North Carolina. I hope to understand how you make decisions on when and where you go for health care. I hope to learn what may influence American Indians to see or not to see a health care provider. I want to focus future studies on what you and your community think is important. This study could help to figure out the next steps to help your community related to getting proper healthcare. I hope that the information I learn can be used to open talks with health providers and policy makers. New talks can help to build partnerships that could help improve care for American Indians. This information and talking may also help to remove barriers that may be causing poor health for American Indians.

Are there any benefits to me for taking part in this research study?

There is no direct help to you by joining this study. You might enjoy the chance to share your feelings about your health care to me or to the group if you join in a group discussion.

Will I get paid for being in the study? Will it cost me anything?

To thank you for joining this study, you will receive \$10.00 cash if you complete the paper survey and the interview or group meeting. There is no payment for completion of ONLY the paper survey. You will receive \$5.00 cash if you attend the follow-up gathering. If you leave the group meeting or one-on-one interview early, you will not receive the \$10.00 cash. If you do not attend the follow-up gathering after the study is complete, you will not receive the \$5.00 cash. The most money you could receive from fully joining the study is \$15.00 cash.

How will you keep my information confidential?

Your information will be handled as carefully as possible. All information written, said or heard is private. The only time your name or information that you give me would be reported is if the law requires me to report it. For example, abuse or neglect would need to be reported to law enforcement. If summary results of this study are shared (written or oral), no names and other personal information will be used.

During the one-on-one interview or group meeting, if a name is spoken and is on the audio recording, I will remove that name when the information is typed. I will use a secure, password protected and firewalled personal laptop computer to carry any typed information until it is stored at the Odum Institute located at UNC at Chapel Hill. My handwritten notes will be typed and stored at the Odum Institute. After I check the notes for accuracy, I will shred the handwritten notes. These notes will not have any of your personal information on them. The paper form that you complete will be made into a (PDF) copy that can be stored at the Odum Institute. Only electronic records will be stored at the secure Odum Institute. No hard copies of any information will be stored at the Odum Institute. The original copy will be kept at Dr. Robin Bartlett's office in a locked filing cabinet. I will store any typed information, to include the information typed from the audio recordings, at The Odum Institute. The Odum Institute will provide a safer place to keep your information. My research team and I will be the only people who can access the information stored at the Odum Institute. The Odum Institute has security with passwords and secure logins. The Odum Institute offers one of the most secure sites for information storage in the Nation. The information that is stored at the Odum Institute will remain there indefinitely. None of these paper will have your name on them.

Within a day of an interview or a group meeting, I will transfer a recording from the tape recorder to my personal secure laptop. Once it is transferred, I will delete the recording from the tape recorder. To get the recording typed into a transcript, I will upload the audio recording to a secure portal with a private transcription company or transcriptionist. This company or transcriptionist will sign a confidentiality agreement. I will also transfer the recordings to a separate secure space through UNC at Chapel Hill. Once they are transferred, I will delete them from my laptop computer. UNC at Chapel Hill has a secure place to store special information like the audio recordings. This storage also requires a special login. I will be the only one who has access to the audio recordings that are stored at UNC at Chapel Hill. After the study is over, and I have reviewed what I learn with you, I will delete the audio recordings. I will ask the people who join the study not to use names while the audio recording is on. There should not be any names on the audio recordings.

All hard copies of any documents that have your signature or name will be locked in a filing cabinet in Dr. Robin Bartlett's office at UNC at Greensboro. For example, your signature will be on this consent form and the receipt for the cash you will receive after the interview, the group meeting, or the follow up meeting. There will not be a master list of the participants in this study. The only people who will have access to papers that you sign are Dr. Bartlett and me. We will shred this consent form and any forms you sign saying you received your \$5 and \$10, three years after the follow-up meeting.

What if I want to leave the study?

If you decide to join the study now, you may stop being in the study at any time. No one will be mad or upset with you if you decide to stop being in the study. It will not change your relationship with UNC at Greensboro, the person that invited you to this meeting, or me. If you decide to stop being in the study, you may ask that any or all of your information be destroyed. I will then shred your information unless I have already removed your personal information and I cannot identify which information is yours. I also

have the right to stop your being in the study at any time. This could be because you have an unexpected reaction, or do not follow instructions, or because the study has been stopped.

What about new information/changes in the study?

If anything changes about the study, I will tell you as soon as I have the information. You may decide to stop the study if you would like to stop.

Voluntary Consent by Participant:

By signing this form you are agreeing that (1) it has been read to you; (2) you fully understand the information on this form, (3) all of your questions concerning this study have been answered; and (4) you are choosing to join this study.

By signing this form you are agreeing that you are 18 years of age or older and are agreeing to join in this study described to you by Betty Nance-Floyd.

Participant's Name *(please print)*

Participant's Signature

Date

Betty Nance-Floyd's Signature

Date

Approved IRB
11/23/15

APPENDIX I

GATEKEEPER FOLLOW-UP GATHERING SCRIPT

Script for American Indian Gatekeeper to invite American Indians in southeastern NC to recruitment meeting

Hello _____, it is _____. I am calling to invite you to the follow-up gathering with my friend Betty Nance-Floyd. You participated in her study earlier and she mentioned she would be having this follow up meeting. You may remember she is studying how American Indians living in southeastern North Carolina think about illness and how we make decisions on when and where we go for health care. She wants to confirm what she learned before she tells other people. She would like to tell you about what she learned at _____ (location) on _____ (date) at ____ PM. I'll be at the meeting, too. The meeting will be held in room _____. You will receive \$5.00 cash if you stay for the meeting. There will be light refreshments served.

Do you think you can attend?

[If answers yes] Great, we will see you then, Thank you. Good bye.

[If answers no] Thank you anyway. Good bye.

APPENDIX J

RESEARCHER JOURNAL

Using Dr. William Marsiglio's *Conducting Qualitative In-depth Interviews* as a guide, the researcher's journal will be part of the qualitative data collection process. The journal will become part of the researcher's data.

Title: *A qualitative study to understand the perception of illness and the decision making process for accessing and utilizing health care for American Indians in southeastern NC.*

The purpose of this study is to understand how American Indians in southeastern NC perceive and experience illness and how they describe their decision making process in regard to access and utilization of health care.

Research Questions

1. How do American Indians in southeastern NC describe illness or being ill?
2. What do American Indians in southeastern NC consider as important factors in their decision making process for accessing health care?
3. What do American Indians in southeastern NC consider as important factors in their decision making process for choosing to utilize health care services

Inclusion criteria: Self-identified American Indians living in southeastern NC, English speaking adults ages 18 and older who agree to participate in a focus group or an interview.

Immediately (within 4 hours) after each interaction with participants, researcher's journal notes will be documented.

The *journal* will have three (3) main parts:

1. **Description** of the interaction to include participant's demographics, setting, time and main highlights of the interaction.
2. **Memos** that are divided into three (3) sections:
 - a. **Theoretical memos** – will summarize the substantive and theoretical ideas that surfaced. What, how, do/could any theories apply? What additional researcher readings will be needed to understand potential theories that have surfaced?
 - b. **Methodological memos** – what happened in the interaction that affected the way it was conducted, the quality of the data, comfort level, or exposure to relevant issues? How can/could that be changed for future interactions. What would I do differently?
 - c. **Personal memos** – how I felt during the interaction (nervous, relaxed, excited, bored, etc). Did I feel inhibited to ask certain questions? How can/would I change this for future interactions?
3. **Field notes** that will be added for each interaction. These notes will be non-verbal communication that was observed during the interaction and will be later added to the transcript.

APPENDIX K

CONFIDENTIALITY AGREEMENT FROM TRANSCRIPTION COMPANY

Statement of Confidentiality for Transcription Services Provided

We at Franklin-Square Services Inc., acknowledge and understand that we have access to confidential data regarding individuals and businesses belonging to our clients.

Therefore, except as required by law and excluding information that can be released under federal or state regulation, we state and agree that we maintain full confidentiality in regards to any and all audio recordings and documentation received from Betty Nance-Floyd, UNC Greensboro **regarding her research project IRB number: 15-0435.**

Furthermore, we agree:

1. To hold in strictest confidence all information and/or the identification of individuals that may be inadvertently revealed during the transcription of audio-recorded interviews or in any associated documents;
2. To not make copies of any audio recordings or digital files of the transcribed interview texts, unless specifically requested to do so by client;
3. To store all study-related audio recordings and materials in a safe, secure location as long as they are in our possession.
4. To delete all electronic files containing study-related documents from our computer hard drives and any backup devices within two week after delivery.

We are aware that we can be held legally liable for any breach of this confidentiality agreement, and for any harm incurred by individuals if we are responsible for disclosure of identifiable information contained in the audio recordings and/or files to which we will have access.

Cornelia Maurer
Manager, Transcription Services
Franklin Square Services INC
Chapel Hill, NC - 919-942-0030

Upload files:

<https://www.hightail.com/u/Franklin-Square-Transcriptions-Fileupload>

APPENDIX L

UNIVERSITY OF NORTH CAROLINA AT GREENSBORO IRB APPROVAL LETTER



OFFICE OF RESEARCH INTEGRITY
2718 Beverly Cooper Moore and Irene Mitchell Moore
Humanities and Research Administration Bldg.
PO Box 26170
Greensboro, NC 27402-6170
336.256.0253
Web site: www.uncg.edu/orc
Federalwide Assurance (FWA) #216

To: Betty Nance-Floyd
School of Nursing

From: UNCG IRB

Date: 11/23/2015

RE: Notice of IRB Exemption

Exemption Category: 2.Survey, interview, public observation

Study #: 15-0435

Study Title: A Qualitative Study to Understand the Perception of Illness and the Decision Making Process for Accessing and Utilizing Health Care for American Indians in Southeastern NC

This submission has been reviewed by the IRB and was determined to be exempt from further review according to the regulatory category cited above under 45 CFR 46.101(b).

Study Description:

Most American Indians (AI) in North Carolina live in rural areas and have limited access to primary health care. There is a growing incidence of chronic illnesses such as strokes, cardiovascular disease, and diabetes among the AI community. The purpose of this study is to understand the perceptions and experiences of illness among American Indians in southeastern NC and to describe their decision making processes when accessing and using health care services.

Focus groups, semi-structured interviews, and field notes will be used for data collection. Analysis will consist of coding of data, sorting themes into patterns, content analysis of the text, making abstractions of understanding of illness and the decision making process in accessing and utilizing health care. After introduction from a community gatekeeper(s), social, healthcare, and church members and leaders will be asked to participate in a survey and one of three to four focus groups. Four to five persons will be asked to participate in an interview. Inclusion criteria are self-identifying American Indians, English speaking adults ages 18-65 who are willing to participate in a focus group or an interview.

Investigator's Responsibilities

Please be aware that any changes to your protocol must be reviewed by the IRB prior to being implemented. Please utilize the most recent and approved version of your consent form/information sheet when enrolling participants. The IRB will maintain records for this study for three years from the date of the original determination of exempt status.

Signed letters, along with stamped copies of consent forms and other recruitment materials will be scanned to you in a separate email. **Stamped consent forms must be used unless the IRB has given you approval to waive this requirement.** Please notify the ORI office immediately if you

have an issue with the stamped consents forms.

Please be aware that valid human subjects training and signed statements of confidentiality for all members of research team need to be kept on file with the lead investigator. Please note that you will also need to remain in compliance with the university "Access To and Retention of Research Data" Policy which can be found at http://policy.uncg.edu/research_data/.

CC:
Tracy Bartlett, School of Nursing

APPENDIX M

UNIVERSITY OF NORTH CAROLINA AT CHAPEL HILL IRB APPROVAL EMAIL

Nance-Floyd, Betty S

From: IRB <irb_no_reply@unc.edu>
Sent: Monday, December 07, 2015 4:48 PM
To: Nance-Floyd, Betty S
Subject: IRB Notice

To: Betty Nance-Floyd
School of Nursing

From: Office of Human Research Ethics

Date: 12/07/2015
RE: Notice of IRB Exemption
Exemption Category: 2.Survey, interview, public observation
Study #: 15-3144

Study Title: A Qualitative Study to Understand the Perception of Illness and the Decision Making Process for Accessing and Utilizing Health Care for American Indians in Southeastern NC

This submission has been reviewed by the Office of Human Research Ethics and was determined to be exempt from further review according to the regulatory category cited above under 45 CFR 46.101(b).

Study Description:

Purpose: Most American Indians (AI) in North Carolina live in rural areas and have limited access to primary health care. There is a growing incidence of chronic illnesses such as strokes, cardiovascular disease, and diabetes among the AI community. The purpose of this study is to understand the perceptions and experiences of illness among American Indians in southeastern NC and to describe their decision making processes when accessing and using health care services.

Participants: Inclusion criteria are self-identifying American Indians, English speaking adults ages 18-65 who are willing to participate in a focus group or an interview.

Procedures (methods): Focus ethnography design. Focus groups, semi-structured interviews, and field notes will be used for data collection. Analysis will consist of coding of data, sorting themes into patterns, content analysis of the text, making abstractions of understanding of illness and the decision making process in accessing and utilizing health care. After introduction from a community gatekeeper(s), social, healthcare, and church members and leaders will be asked to participate in a survey and one of three to four focus groups.

Investigator's Responsibilities:

If your study protocol changes in such a way that exempt status would no longer apply, you should contact the above IRB before making the changes. There is no need to inform the IRB about changes in study personnel. However, be aware that you are responsible for ensuring that all members of the research team who interact with subjects or their identifiable data complete the required human subjects training, typically completing the relevant CITI modules.

The IRB will maintain records for this study for 3 years, at which time you will be contacted about the status of the study.

The current data security level determination is Level II. Any changes in the data security level need to be discussed with the relevant IT official. If data security level II and III, consult with your IT official to develop a data security plan. Data security is ultimately the responsibility of the Principal Investigator.

Please be aware that approval may still be required from other relevant authorities or "gatekeepers" (e.g., school principals, facility directors, custodians of records), even though the project has determined to be exempt. .
IRB Informational Message - please do not use email REPLY to this address